Transgender

POPULATION FACT SHEET: AUGUST 2012

TRANSGENDER PEOPLE

Transgender describes someone who identifies with a gender that differs from their assigned sex at birth. As a traditionally marginalized and underserved population, transgender people face significant and unique barriers to accessing care.

SURVEILLANCE

Data on HIV prevalence in the transgender community are hindered by a lack of uniform collection at the national level. As a result, the total number of transgender people who are HIV positive remains unknown. Recent studies place HIV prevalence in this population among the highest in the Nation.[1,2]

Transgender Women

A transgender woman, or transwoman, is someone who was assigned as male at birth, but identifies as a woman and has a female gender identity. Transwomen are also referred to as male-to-female, or MTF.

- It is estimated that transwomen suffer from HIV infection rates greater than any other subpopulation, including very high-risk populations such as men who have sex with men (MSM) and partners of people living with HIV/AIDS (PLWHA).
- A U.S. Centers for Disease Control and Prevention (CDC) meta-analysis of 29 studies found an average weighted HIV prevalence rate of 16 percent among transwomen in studies where participants self-reported their HIV infection. However, in studies where participants were tested, the average weighted prevalence rate was even higher at 28 percent.[1] This underscores the need for increased HIV testing and outreach with this population.
- The same meta-analysis found that African-American transwomen were particularly affected, reporting prevalence of HIV infection at 56 percent when tested, and 31 percent self-reported.[1]

Transgender Men

A transgender man, or transman, also known as female-to-male (FTM), is someone who was assigned as female at birth, but identifies as a man and has a male gender identity.

- Compared with transwomen, HIV prevalence is relatively low in transmen based on the data that is currently available. Studies report only around 1 to 3 percent of transmen are infected with HIV. However, transmen may still be at risk for infection, and more data are needed to better understand how HIV affects this population.[3,4,5]
- Although HIV prevalence among transmen is much less than among transwomen, a study of transmen who have sex with nontransmen (commonly referred to as gay transmen or trans MSM) found they consistently reported not using condoms during receptive anal or vaginal sex.[6] Although trans MSM have reportedly low incidence, their sexual partners (nontrans MSM) have high rates of HIV, placing trans MSM at increased risk for HIV infection.

CRITICAL ISSUES

Health Care Issues

Transgender people face a host of unique and population-specific health disparities and challenges that contribute to their risk for HIV. There is a great deal of mistrust of the health care system in this population, since many transpeople have had negative experiences with health care providers.[7] Misinformation and misconceptions about transgender people are prevalent.

Transgender people are often viewed as a single demographic, but this community is very diverse with some particularly unique aspects. Transpeople may identify with different sexual or gender identities, may not self identify as "trans," and may or may not seek hormonal or sexual reassignment surgery. This can make engaging transgender people in care especially difficult.[8]

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Legal and Systemic Barriers

Transgender people encounter many systemic and legal barriers to care services. Hormone therapy and sexual reassignment procedures are rarely covered by health insurance carriers. Barriers to substance abuse treatment can arise from provider insensitivity, strict gender segregation in in-patient settings, and hormone use viewed as continuing substance abuse.[9,10,11]

Transpeople's name and gender often do not match those shown on identification documents, which only use sex as an identifier. This can cause obstacles to not only health care access but also to employment and to Social Security.[7] Identification problems arise in electronic medical records as well, which often do not have transgender-specific options for sex/gender fields.[12]

Discrimination

Transgender people struggle against an overwhelming societal stigma. This is exacerbated by misinformation, a lack of public understanding of the needs of this population, and the lack of appropriate training for medical providers. This constant stigma can lead to lower self-esteem and depression. Transpeople also suffer from social marginalization, which manifests itself in the denial of employment, housing, and educational opportunities.[13]

High Risk Behaviors

Some transwomen use silicone injection as a faster, cheaper alternative to cosmetic surgery and hormone therapy to achieve a more feminine physique. However, there are many health risks associated with silicone injection. Transwomen may attend "pump parties" where they take turns injecting silicone, often in unsanitary conditions. The sharing of injection needles carries the risk for HIV and hepatitis. Silicone can harden and migrate over time, leading to serious systemic illness, disfigurement, or in some cases even death.[14]

Risk of HIV infection in transwomen is exacerbated by the high proportion of the transgender population that is engaged in survival sex and sex work. One study reported that over one-half of transwomen had a history of sex work. Transwomen may also be driven to survival sex and sex work because of homelessness as a result of housing and employment discrimination.[1,3,15,16]

Sexual and physical violence against transwomen is another significant concern. The San Francisco Health Department found that 59 percent of transwomen in their study had been raped, while another study reported that over 50 percent had been harassed, with 25 percent reporting that they were victims of violent incidents.[7,17,18,19]

THE RESPONSE OF THE HIV/AIDS BUREAU

In 2010, 4,269 transgender people (.8 percent of all clients) were served by the Ryan White HIV/AIDS Program.*

The Health Resources and Services Administration (HRSA), HIV/AIDS Bureau is committed to providing the highest quality care, as well as broadening its capacities to address the needs of the transgender community. In 2011, HRSA released a comprehensive *HRSA CAREAction* newsletter and accompanying online resource guide about transgender health and HIV/AIDS (see http://hab.hrsa.gov/deliverhivaidscare/careactionnewsletter.html).

HRSA has supported efforts to bolster and develop community-based health care networks that reduce barriers to early HIV identification and ensure entry to high-quality primary health care among at-risk populations. In 2005, HRSA convened a community consultation meeting to discuss barriers to transgender care and ways to meet the needs of this population (see www.careacttarget.org/library/TransgenderReport.pdf).

Other HRSA materials addressing the impact of HIV/AIDS among the transgender population include a best practices document for transgender health (see http://careacttarget.org/library/tgguidelines.pdf). HRSA is also launching a Special Projects of National Significance (SPNS) project specifically targeting transgender populations, scheduled to begin in September 2012.

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* U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB). *2010 Ryan White HIV/AIDS Program Services Report.*

NOTES

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Transgender

HIV surveillance data on transgender people is not uniformly collected by HIV surveillance systems.[1] As a result, minimal epidemiological data are available on new HIV diagnoses and persons living with HIV among transgender individuals both nationally and in the Houston Area.[1] The epidemiological data that are available are presented below. Discrepancies exist between these two data sources due to data collection differences between surveillance and care data management systems.

(**Table 1**) In 2011, eight new HIV diagnoses and 10 new AIDS diagnoses were reported among transgender persons in Houston/Harris County. This equates to 0.6% of all new HIV diagnoses and 1.3% of all new AIDS diagnoses made in the jurisdiction in that year. In addition, transgender persons were 0.1% of all persons living with HIV in Houston/Harris County at the end of 2010.

TRANSGENDER TABLE 1-New Diagnoses of HIV and AIDS and People Living with HIV Disease in Houston/Harris County[a]

	Cases of New HIV Disease, 2011[b]	Cases of New AIDS, 2011[c]	Persons Living with HIV Disease, 2010[d]
Total Transgender[¶]	8	10	29
Total All Persons	1,249	775	20,002

[a]Source: Houston/Harris County eHARS
[b]HIV Disease = People diagnosed with HIV, regardless of AIDS status, with residence at diagnosis in Houston/Harris County in 2011
[c]New AIDS = People diagnosed with AIDS with residence at diagnosis in Houston/Harris County in 2011
[d]PLWH at end of 2010 = People living with HIV disease, regardless of AIDS status, in Houston/Harris County at the end of 2010
[¶]This category is not stratified further because of a small number of cases. All cases indicated male natal sex and current female full-time gender expression, or MtF.

(**Table 2**) In 2011, 68 transgender persons HIV were served by the Ryan White HIV/AIDS Program in the Houston EMA. This equates to 0.6% of all Ryan White clients served in that year. Of the 68 transgender clients documented, 23.5% were new to care.

TRANSGENDER TABLE 2-Number of Clients Served by the Ryan White HIV/AIDS Program Part A, B, MAI, and State Services in the Houston EMA/HSDA, 2011

	Total Clients Served	New Clients Served
Total Transgender	68	16
Total All Persons Served	11,184	2,401

Source: Ryan White Grant Administration and The Resource Group. All Services/All Grants. Presented 4/12/12

[1]Centers for Disease Control and Prevention, "HIV Infection among Transgender People." August 2011.

Access to HIV Care among Transgender and Gender Non-Conforming People in Houston

A Special Study of the Houston Area Ryan White Planning Council
February 12, 2013

BACKGROUND

The Houston Area Ryan White Planning Council is responsible for designing HIV care, treatment, and support services for people living with HIV/AIDS in the Houston Eligible Metropolitan Area (EMA). The Planning Council uses several sources of information in order to meet this mandate, including epidemiological profiles, service-utilization reports, and a community-wide needs assessment of HIV-positive individuals conducted every three years. When specific populations are underrepresented in current data sources, the Planning Council may also commission a special data collection effort, or *Special Study*, to fill data gaps.

In 2012, the Planning Council released its comprehensive HIV prevention and care services plan for the Houston Area. In it are the specific HIV-infected populations in the Houston EMA with insufficient data for assessing their current level of access to HIV services. In response, the Planning Council commissioned a series of Special Studies to gather data on each underrepresented group. This article presents the results of the Planning Council's first Special Study in the series, focused on transgender and gender non-conforming people living with HIV/AIDS in the Houston EMA.

INTRODUCTION

Transgender individuals are among the highest risk for HIV infection in the U.S. today. [1] Moreover, the challenges often faced by transgender individuals in regards to discrimination, stigma, lack of resources, and other social determinants can make it difficult for them to access HIV services.[1] One study of transgender people living with HIV/AIDS showed a statistically lower rate of HIV treatment when compared to nontransgender people.[2] For these reasons and others, transgender communities are a high priority for HIV prevention, linkage, and retention in care efforts both nationally and in the Houston EMA.[3]

However, relatively little is known about the specific needs, gaps, and barriers to HIV care among transgender people in the Houston EMA. Transgender individuals are less than 1% of all Ryan White HIV/AIDS Program clients in the EMA,[4] and only 22 transgender-identified individuals participated in the EMA's most recent community-wide needs assessment of people living with HIV/AIDS.[5] This Special Study sought to describe the HIV service utilization patterns of transgender people living with HIV/AIDS in the Houston EMA, including socio-economic or behavioral factors that may be influencing their use of services, and to establish baselines for core HIV prevention and care indicators, including linkage to care and unmet need.

METHODS

Participants were self-selected, self-identified transgender HIV-positive adult residents of the Houston EMA. Because many individuals may not identify with the term "transgender," inclusion screening questions used the broader terminology of "transgender or gender non-conforming" and offered both a definition of the term and examples along a broad continuum of gender expression. The text for the transgender inclusion screening question for the study was: [6]

> **"Do you consider yourself to be transgender or gender non-conforming in any way?**
> Transgender/gender non-conforming refers to people whose gender identity or expression is different, at least part of the time, from the sex assigned to them at birth

on their birth certificate. Below are some examples of people who might consider themselves transgender:

MTF (male to female)	Drag performer (queen or king)
FTM (female to male)	Genderqueer
Part time as one gender/part time as another	Genderfluid
	Feminine male
Transgendering	Masculine female
Transsexual	Third gender
Cross dresser	Two spirit
Androgynous	

Please check one:

- ▢ Yes, I consider myself to be transgender or gender non-conforming in some way
- ▢ No. If no, please do NOT continue with the survey"

In addition, following national recommendations, [1] the two-step data collection method of asking sex assigned at birth and current gender expression was also used. Sexual orientation identification was also asked separately.

Our primary data collection method was a survey that addressed three overall topics: HIV diagnosis and linkage to care; HIV service needs, gaps, and barriers; and social determinants. Demographics were also collected. To participate, individuals could self-administer surveys online, in hard-copy by mail, or in hard-copy in-person at designated survey sites; they could also complete surveys via staff interview by telephone or in-person. Two trained interviewers conducted the surveys. Recruitment occurred through social promotion (i.e., flyers and postcards at bars, clubs, community centers, clinics, community-based organizations, and housing complexes), social media, staff promotion, and word of mouth. Surveys were voluntary and anonymous, and all participants were offered a $20 gift card. Surveys were collected from August 27, 2012 through December 13, 2012.

This study was intended to be descriptive in nature; therefore, no sampling methods or control groups were used. Participation was non-identifying, and the results are self-reported. Data collection methods and survey questions were reviewed and approved by an advisory committee of transgender-identified community members, leaders, and gatekeepers as well as researchers with experience studying transgender populations (See Acknowledgments). Survey Monkey was used for data storage; and analysis was conducted in Microsoft Excel. Consistent with a descriptive study, no statistical tests were performed, and it is unknown if the comparisons presented here are significant.

SAMPLE

(See Table 1) A sample of 135 transgender or gender non-conforming people living with HIV/AIDS in the Houston EMA is included in this analysis.[7] Forty percent (40%) of the sample was natal males with a primary full-time current gender expression and/or identity of female (MtF), and 8% was natal females with a primary full-time current gender expression and/or identity of male (FtM) (a ratio of 5:1). An additional 37% had part-time discordant natal sex and current gender expression and/or identity, and 14% had concordant natal sex and current gender

expression and/or identity, though still identified as transgender or gender non-conforming. The average age of the sample was 40 years (standard deviation = 10.8; range = 19 - 63).

The sample was comprised of 77% African Americans, 17% White, non-Hispanics, 8% Hispanics, and 4% other, which is an overrepresentation of African Americans (and an underrepresentation of other racial/ethnic groups) when compared to current HIV/AIDS prevalence in the Houston EMA.[8]

The majority of the sample had at least a high school diploma or GED (69%), while 31% reported less than a high school education, which is 1.6 times higher than the percent reported by the general population of people living with HIV/AIDS in the Houston EMA (19%). At 47%, the sample reported more disability than the general HIV-positive population (39%) and only slightly less full- or part-time employment (16% vs. 18%). The percent of respondents living in their own home or apartment (38%) was 2.0 times less than the general HIV-positive population (77%), and the percent living in a group home for people who are HIV-positive (30%) was 2.3 times higher (13%). No-one in the sample reported living in a shelter, car, or on the street.

TABLE 1-Demographic Comparison of Participating Transgender People Who Are HIV Positive (n=135) and the General HIV-Positive Population in the Houston Area

	Transgender Participants	General HIV+ Population
Transgender Identification		
Natal male/female expression (MtF)	40%	--
Natal female/male expression (FtM)	8%	--
Part-time male/female	37%	--
Non-variant	14%	--
Age, mean (sd)	40.2 (10.8)	44.7 (10.0) [a]
18-24	9%	3%
25-44	47%	44%
45+	44%	54%
Race/Ethnicity		[b]
White, non-Hispanic	17%	25%
African American	77%	50%
Hispanic	8%	23%
Other	4%	2%
Education		[a]
Less than high school	31%	19%
High school diploma/GED	58%	38%
Technical degree or above	11%	42%
Employment Status		[a]
Employed FT/PT	16%	18%
Temporary/seasonal/contract	5%	5%
Student	8%	--
Retired	4%	3%
Unemployed	28%	35%
Disabled/not working	47%	39%
Housing Status		[a]
Own house/apartment	38%	77%
With friends/family	25%	--
Group home	30%	13%
Shelter, car, street	0%	11%
Combination/changes often	7%	--
Incarceration History	20%	19%[a]
Years of HIV Diagnosis (sd)	12.2 (8.2)	11.2 (7.3)[a]

[a]2011 Houston Area HIV/AIDS Needs Assessment, April 2011 (n=924). Conducted in the Houston Eligible Metropolitan Area (EMA) of Chambers, Fort Bend, Harris (including the City of Houston), Liberty, Montgomery, and Waller Counties
[b]Texas eHARS (as of 12/31/2011). Jurisdiction is Houston EMA

Twenty percent (20%) of the sample reported being released from a correctional facility in the last 12 months, which is comparable to the general HIV-positive population in the Houston EMA (19%).

The average length of HIV diagnosis in the sample was 12 years (standard deviation = 8.2; range = 0 - 30) with 8% diagnosed for one year or less.

RESULTS

HIV Testing, Diagnosis, and Linkage to Care

The first topic we wanted to address through this study was what motivates transgender people in the Houston EMA to test for HIV and where they test. In our sample, the most commonly-cited reason for testing was feeling sick (25%), followed by receiving an HIV test as part of a routine health check-up (21%). Three percent (3%) of the time the reason for testing was the recommendation of a medical provider, and another 3% was in response to community advertising, The most common location for HIV testing was a dedicated HIV clinic (34%), followed by an ER or hospital (17%). Thirteen percent (13%) said they were tested at a health department, and 9% were tested in jail or prison.

Because treatment for HIV can extend life expectancy and quality of life for those infected, length of time for linkage to care post-diagnosis and current care status are used as indicators of community health related to HIV both nationally and locally.[3,9] At the time of this study, baselines were missing for both of these measures for the transgender population in the Houston EMA. Therefore, the next topics we sought to address in the study were linkage to care and patterns of care. We asked respondents when they first saw a doctor for HIV following their diagnosis (either within three months or more than three months, per the federal benchmark[9]) and if they were currently meeting the national definition of being in care, which is defined as completing at least one of the following in the last 12 months: (1) seen a doctor for HIV, (2) taken HIV medications, (3) had an HIV viral load test, or (4) had a CD4 count test.[10]

(See Table 2) The majority of the transgender people in this study was linked to care within three months of their HIV diagnosis (76%). This percentage is comparable to current estimates for the Houston EMA as a whole (77%), [11] though lower than both local and national goals.[3,9] For those in the sample who did report delayed care, the most commonly-cited reason was denial about being HIV-positive (80%). However, 16% of the time the reasons were lack of knowledge about where to go for HIV services, fear about how the medical staff would react to their gender variance, and fear about how other clients would react. Twelve percent (12%) of the time the reason for delayed care was having to disclose their gender variant status to providers and staff.

TABLE 2-Linkage to Care among Participating Transgender People Who Are HIV Positive (n=133) Compared to the General HIV-Positive Population in the Houston Area and Local and National Goals

	Transgender Participants	General HIV+ Population[a]	Goal[b]
Linked to HIV Care within 3 Months of Diagnosis	75.9%	77.4%	85.0%

[a]Texas Department of State Health Services, 8/20/12
[b]National HIV/AIDS Strategy for the United States (July 2010); Houston Area Comprehensive HIV Prevention and Care Services Plan (2012 – 2014)

The majority of the people in this study was also currently in care (97%). This percentage far exceeds estimates for the general HIV-positive population in the Houston EMA (75%).[12] This is most likely a bias in our sample, rather than a true unmet need result, due to study recruitment taking place at HIV clinics and HIV group homes. Therefore, no additional analysis was performed on this data point.

HIV Care Service Utilization, Barriers to Care, and Service Needs

(See Table 3) Another topic we wanted to explore in this study was the use of specific HIV care, treatment, and support services by transgender people in the Houston EMA. To do this, we

TABLE 3-HIV Care Services Used and Barriers Reported by Participating Transgender People Who Are HIV Positive (n=132) in the Houston Area

Service Category (in order)	Reporting Use of Service # (%)	Service Category (in order)	Reporting Barrier to Use # (%)
Primary HIV care	113 (85.6)	Oral health care	28 (21.2)
Transportation	76 (57.6)	Primary HIV care	23 (17.4)
Case management	64 (48.5)	Case management	23 (17.4)
Oral health care	60 (45.5)	Transportation	18 (13.6)
Mental health counseling	59 (44.7)	Medical nutritional therapy	15 (11.4)
Medical nutritional therapy	51 (38.6)	Mental health counseling	13 (9.8)
HIV medication assistance	46 (34.8)	Legal services	8 (6.1)
Substance abuse treatment	28 (21.2)	Health insurance assistance	7 (5.3)
Health insurance assistance	25 (18.9)	Hospice care	7 (5.3)
Legal services	21 (15.9)	HIV medication assistance	6 (4.5)
Day treatment	19 (14.4)	Day treatment	6 (4.5)
Language services	14 (10.6)	Substance abuse treatment	4 (3.0)
Hospice care	9 (6.8)	Language services	4 (3.0)

asked each respondent if, in the past 12 months, they had used each of the services that the Planning Council had prioritized for funding through the Ryan White HIV/AIDS Program and if they had experienced any difficulties accessing each of the services, regardless of recent use. Primary HIV care (86%), transportation (58%), and clinic-based case management (49%) were the most used services in past 12 months. The services cited most often as having difficulties to access were oral health care (21%), primary HIV care (17%), and clinic-based case management (17%). These findings are consistent with the general population of HIV-positive people in the Houston EMA.[13]

(See Table 4) Specific barriers faced by this population when seeking HIV services were also explored. When asked what barriers, if any, respondents had faced at any time since their diagnosis, the most commonly-cited was lack of transportation (44%). Also high on the list was being treated poorly by staff due to gender variance (29%), lack of funds to pay for services (28%), and denial about being HIV-positive (24%). In addition, 19% of respondents reported lack of provider familiarity with transgender needs as a barrier to care. Twenty-two percent (22%) reported no barriers. When compared to

TABLE 4-Most Commonly-Cited Specific Barriers to HIV Care Reported by Participating Transgender People Who Are HIV Positive (n=105) Compared to the General HIV-Positive Population in the Houston Area

Specific Barrier Experienced (in order)	# (%) Reporting	Rank among General HIV+ Population[a]
No transportation	46 (43.8)	6
Treated poorly by staff due to being transgender	30 (28.6)	--
No money, the services cost too much	29 (27.6)	11
Fear or denial about being HIV-positive	25 (23.8)	14
Wait times for services were too long	20 (19.0)	3
Hard to get an appointment for HIV services	20 (19.0)	5
Providers are not familiar with transgender needs	20 (19.0)	--
A problem with drugs or alcohol	18 (17.1)	--
Lack of housing	18 (17.1)	--
Felt fine, not sick, "didn't think I needed HIV care"	16 (15.2)	--
HIV care a low priority	16 (15.2)	--
No Barriers Experienced	30 (22.2)	--

[a]2011 Houston Area HIV/AIDS Needs Assessment, April 2011 (n=924). Ranking is for core and support services combined; no distinction between type of service was made in our study.

the general population of HIV-positive people in the Houston EMA, some differences emerged.[14] For example, while lack of transportation is the highest ranking barrier to HIV care among our sample (when barriers existed), it ranked sixth among the HIV-positive population as a whole. Similarly, lack of funds ranked third in our sample (when barriers existed) yet eleventh among all HIV-positive persons in the Houston EMA.

This section of our survey also asked respondents if more or different services are needed by transgender people living with HIV/AIDS in the Houston EMA to more effectively manage HIV disease. The top five categories of responses were: (1) more housing, including rental assistance and shelters for transgender persons, (2) more transportation services, (3) assistance with basic needs such as food and clothing, (4) support groups for transgender persons, and (5) employment assistance for transgender persons.

TABLE 5-Comparison of Risk Behaviors and Co-Morbidities among Participating Transgender People Who Are HIV Positive and the General HIV-Positive Population in the Houston Area

	Transgender Participants	General HIV+ Population[a]
Risk Activities, last 6 mo.		
Sex with someone known to be HIV+	39%	30%
Anonymous sex partner	30%	16%
Sex bartering	15%	6%
Shared needles/injection equipment	3%	1%
Had sex with known needle-sharer	5%	--
Condom Use		
No condom at last sexual activity	26%	30%
Does not *always* use condoms	60%	50%
Diagnosed with STD, last 6 mo.	13%	--
Mental Health Concern, last 30 days	70%	63%
Anger management	26%	24%
Anxiety	54%	52%
Depression	62%	--
Fear of leaving the home	6%	--
Wanting to harm themselves	17%	9%
Attempt at self-harm	6%	--
PTSD	6%	--
Mental health concern requiring medication	44%	27%
Experience with Discrimination		
Been treated differently	84%	--
Been denied services	17%	--
Been asked to leave a public place	16%	--
Experience with Violence		
Verbal harassment/taunts	60%	--
Threats of violence	36%	--
Physical assault	30%	--
Sexual assault	23%	--
Rape	16%	--

[a]2011 Houston Area HIV/AIDS Needs Assessment, April 2011 (n=924)

Risk Activities, Co-Morbidities, and Discrimination History

Multiple national studies of transgender people and two studies conducted in the Houston community[15, 16] have suggested that risk behaviors for HIV transmission are common in the transgender population as are other health concerns such as depression or substance abuse that can hinder the ability to access and maintain HIV care. We wanted to assess the frequency of these types of behaviors among HIV-positive transgender persons in the Houston EMA as well (See Table 5).

In our sample, sexual activities known to increase HIV transmission risk were reported more often than in the general HIV-positive population in the Houston EMA, [13] with one exception. In our sample, a slightly lower percentage of respondents reported no condom during their last

sexual activity (26%) than did the population as a whole (30%). However, a higher percentage of our respondents (60%) reported not *always* using condoms during sexual activity than did the general population (50%). Also of note, 13% of our sample reporting being diagnosed with an STD other than HIV in the last six months.

Results related to co-occurring concerns were varied. A higher percentage of the respondents in our sample (70%) than in the general HIV-positive population in the Houston EMA [13] reported having a least one mental health concern in the past 30 days; however, comparable and lower percentages reported a concern with alcohol use or drug use, respectively. Of note, however, is the difference in frequency of *type* of mental health concern reported. Among the HIV-positive transgender persons in our sample, 17% reported wanting to harm themselves compared to 9% of the general HIV-positive population. Moreover, 44% of our sample reported having a mental or emotional problem severe enough to require prescription medication compared to 27% of the general HIV-positive group.

Lastly, our study also sought to describe the local transgender HIV-positive population's experience with gender variant-related stigma, discrimination, and violence. The results were high, with 84% of respondents reporting receiving differential treatment in public due to gender variance, including 16% who reported being asked to leave a public place. In addition, 60% of respondents reported being harassed or taunted due to their gender variant status, 36% reported being threatened with violence, and 30%, 23%, and 16% reported being the victims of physical assault, sexual assault, and rape, respectively, at some time in their lives.

LIMITATIONS

There are limitations to this study. Respondents were self-identified and self-selected according to provided definitions of inclusion criteria. Though the broad scope terminology utilized at screening may have produced a more inclusive sample of respondents, the lack of a random sample, sampling frame, control group, and statistical testing lessens the study's generalizability, and results may not be fully representative of the study population as a whole. To mitigate this limitation, comparisons have been provided between study results and those found in larger samples. Respondent self-selection can also result in duplication as do some of the recruitment methods used in the study, such as incentives and word of mouth promotion. A data matching protocol was applied post-data collection in order to reduce potential duplication. Another limitation is the use of mixed-methods for data collection, which resulted in both self- and interviewer-administration of the survey tool. While this approach may have reduced barriers to participation in the study, it may also have lessened the accuracy of the survey instrument and produced variability between respondents. Data collected by the tool were also self-reported, and confirmation was not possible due to study design. As a result, there is no way to validate the individual experiences described by respondents, and the results presented here should not be interpreted or used as verification of service delivery or health outcomes.

DATA SUPPLEMENT—FOCUS GROUP RESULTS

Three focus groups were held in October 2012 to complement the quantitative results of this Special Study. The goal of the focus groups was to better understand the perspectives of HIV-positive transgender clients in the Houston EMA in regards to their HIV status and to hear directly from clients about opportunities for improving the HIV system of care. A total of 14 self-identified and self-disclosed transgender HIV-positive individuals participated in the series. Key themes from their discussions are described below.

Gender variance is perceived as having greater stigma than HIV. Focus group participants were asked to describe what daily life is like as a transgender identified person living with HIV. For most participants, being gender variant was a greater source of concern than being HIV-positive. Said one participant, "that's a worse stigma, [being] gay or transgender, than the disease itself." According to focus group participants, this often results in transgender people isolating themselves from the public and from needed HIV services out to fear of others knowing they are transgender. Explained a participant, "A lot of transgender people are afraid to come out. A lot of them feel fear [about] how they're going to be received."

The HIV medical home is an effective model for transgender clients. Because many transgender identified persons may be fearful of public reaction, an HIV medical home or "one-stop-shop" was cited as a preferred model for HIV care for this population, and a dedicated HIV clinic was identified as the preferred type of provider. According to focus group participants, fear about disclosure of and/or differential treatment due to being gender variant or HIV-positive is a main reason why transgender people are out of care. Explained a participant, "They say, if they go to the doctor and see someone they know, they will tell their business. At [an HIV clinic], everybody is the same. They already know." Said another participant, "They [the HIV clinic] deal with one situation, HIV…you walk in, and everyone's going through the same thing." A third participant noted, "When you go to an [HIV clinic], they give you the same treatment. They are going to treat you with respect." In addition, HIV clinics that "cater to" transgender clients were also praised, with one participant describing them as "wonderful."

Increased capacity for serving gender variant clients remains a system wide need. Participants in all three groups described repeated interactions with HIV providers who were "insensitive" to their transgender status, particularly in regards to pronoun usage and name. Explained one participant, "You know [your client] is a male, but she's dressed as a female. But, the first thing that comes out of your mouth is 'excuse me, *sir*, can I help you.' That makes the client uncomfortable. There's no way I can discuss my problems, concerns, needs, frustrations when you've just disrespected me." Participants had the overall impression that staff at HIV clinics are hired without regard to their experience working with transgender clients.

Discrimination appeared to be more pronounced in the broader social service community than in the HIV services arena. Said one participant, "It is easier for [non-transgender people] to walk up and get services, like shelter. Even going to certain clothing closets. They said you can only get male clothes. I don't dress as a man, so why should I get male clothing?" Training on client-centered pronoun usage, name usage, and improving the gender variant sensitivity of policies and procedures were all identified as potential solutions. When describing a positive experience regarding pronoun usage following a change in policy, one participant said, "It's not something you're already used to. It's something that somebody had to tell you [to do]."

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4. Harris County Public Health Services, Ryan White Grant Administration. Total number of net unduplicated clients served in calendar year 2011 by the Ryan White HIV/AIDS Program Part A, B, State Services and Minority AIDS Initiative (MAI). Run 4/12/12. Source: Centralized Patient Care Data Management System
5. Houston Area Ryan White Planning Council, 2011 Houston Area HIV/AIDS Needs Assessment, April 2011.
6. This text was modeled on terminology used in the National Transgender Discrimination Study (See Grant, JM et al., *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey*. Washington: National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011).
7. Unique identifying information was not collected on survey respondents, and surveys could be completed without in-person contact with an interviewer as well as through self-administration. This created the potential for duplicate respondents and for survey completion by individuals who did not meet screening criteria. Various de-duplication and authentification methods were applied throughout the study, and only results from the subsequent data set are presented here. A total of 142 surveys were completed; and 135 were determined to be non-duplicates meeting the screening criteria.
8. Living HIV/AIDS cases in the Houston EMA as of December 31, 2011. Source: Texas eHARS.
9. National HIV/AIDS Strategy for the United States (July 2010).
10. Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB)
11. Texas Department of State Health Services. New Dx Cases with Met Need But No Linkage to Care Dates, 2011.
12. Texas Department of State Health Services. Number & Proportion of PLWHA with Unmet Need for Medical Care by EMA/TGA, 2011
13. Respondents in the community wide needs assessment of the general HIV-positive population in the Houston EMA were asked to indicate if they "had difficulty" accessing core medical and support services funded by the Ryan White HIV/AIDS Program. Core medical services that respondents reported most often as having "some difficulty getting" were oral health care (29%), HIV medication assistance (20%), clinic-based case management (18%), and primary HIV care (17%). Source: Houston Area Ryan White Planning Council, 2011 Houston Area HIV/AIDS Needs Assessment, April 2011.
14. When respondents in the community wide needs assessment of the general HIV-positive population in the Houston EMA indicated difficulty accessing core medical or support services funded by the Ryan White HIV/AIDS Program, they were subsequently asked what specific barrier they encountered. Most commonly cited barriers were (1) lack of knowledge about where services are offered, (2) lack of knowledge about how to access services, (3) wait times, (4) ineligibility for services, (5) difficulty making or keeping appointments, (6) transportation, (7) paperwork, (8) inconvenient location, (9) poor treatment by agency staff, (10) perception of ineligibility for services, (11) inability to pay for services, (12) fear of disclosure of status, (13) language barriers, and (14) denial about being HIV-positive. Source: Houston Area Ryan White Planning Council, 2011 Houston Area HIV/AIDS Needs Assessment, April 2011.
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HIV Infection among Transgender People

August 2011

Fast Facts

Transgender communities in the United States are among the groups at highest risk for HIV infection.

In 2009, among transgender persons, the highest percentage of newly identified HIV infection was among blacks and Hispanics.

Many cultural, socioeconomic, and health-related factors contribute to the HIV epidemic and prevention challenges in the U.S. transgender community.

Transgender communities in the United States are among the groups at highest risk for HIV infection. Transgender people are *gender identity* minorities. The term gender identity refers to a person's basic sense of self, of identifying as male, female, or some other gender (e.g., transgender, bigender, intersex). Transgender refers to people whose gender identity does not conform to norms and expectations traditionally associated with a binary classification of gender based on external genitalia, or, more simply, their sex assigned at birth. It includes people who self-identify as gender variant; male-to-female (MtF) or transgender women; female-to-male (FtM) or transgender men; many other gender nonconforming people with identities beyond the gender binary; and people who self-identify simply as female or male. Gender identity, gender expression, and sexual orientation are separate, distinct concepts, none of which is necessarily linked to one's genital anatomy.

The Numbers

Because surveillance data for this population are not uniformly collected, information is lacking on how many transgender people in the United States are infected with HIV. However, data collected by local health departments and scientists studying these communities show high HIV positivity among transgender people.

- Data from CDC-funded HIV testing programs show high percentages of newly identified HIV infections among transgender people. In 2009, about 4,100 of 2.6 million HIV testing events were conducted with someone who identified as transgender. Newly identified HIV infection was 2.6% among transgender persons compared with 0.9% for males and 0.3% for females. Among transgender persons, the highest percentage of newly identified HIV infection was among blacks (4.4%) and Hispanics (2.5%). More than half (52%) of testing events with transgender persons occurred in non-clinical settings.
- In New York City, from 2005–2009, there were 206 new diagnoses of HIV infection among transgender people, 95% of which were among transgender women. Approximately 90% of MtF and FtM people newly diagnosed with HIV infection were black or Hispanic. Newly diagnosed transgender people were more likely to have been in their teens or twenties than their non-transgender counterparts. Also, among newly diagnosed people, 50% of transgender women had documentation in their medical records of substance use, commercial sex work, homelessness, incarceration, and/or sexual abuse as compared with 31% of other people who were not transgender.
- Findings from a meta-analysis of 29 published studies showed that 27.7% of transgender women tested positive for HIV infection (4 studies), but when testing was not part of the study, only 11.8% of transgender women self-reported having HIV (18 studies). In one study, 73% of the transgender women who tested HIV-positive were unaware of their status. Studies also indicate that black transgender women are more likely to become newly infected with HIV.

Prevention Challenges

Many cultural, socioeconomic, and health-related factors contribute to the HIV epidemic and prevention challenges in the U.S. transgender community. These include higher rates of drug and alcohol abuse, sex work, incarceration, homelessness, attempted suicide, unemployment, lack of familial support, violence, stigma and discrimination, limited health care access, and negative health care encounters.

- **Identifying transgender people** can be challenging. Using gender alone is not enough because some people in this community do not self-identify as transgender. Using the 2-step data collection method of asking for sex assigned at birth and current gender identity increases the likelihood that all transgender people will be accurately identified. It is important to avoid making assumptions about sexual orientation and sexual behavior based on gender identity as there is great diversity in orientation and behavior among this population, and some identify as both transgender *and* gay, bisexual, or lesbian. The Institute of Medicine has recommended that behavioral and surveillance data for transgender men and women should be collected and analyzed separately and not grouped with data for men who have sex with men (MSM).

Additional Resources:

CDC HIV and AIDS
www.cdc.gov/hiv
Visit CDC's HIV and AIDS Web site.

CDC-INFO
1-800-CDC-INFO or 1-800 (232-4636)
cdcinfo@cdc.gov
Get information about personal risk, prevention, and testing.

CDC National HIV Testing Resources
www.hivtest.org
Text your ZIP code to KNOW IT or 566948.
Locate an HIV testing site near you.

CDC National Prevention Information Network (CDC NPIN)
1-800-458-5231
www.cdcnpin.org
Find CDC resources and technical assistance.

AIDSinfo
1-800-448-0440
www.aidsinfo.nih.gov
Locate resources on HIV and AIDS treatment and clinical trials.

For more information, visit the CDC HIV Web site at www.cdc.gov/hiv

- **High levels of HIV risk behaviors** have been reported among transgender people. HIV infection among transgender women is associated with having multiple sex partners and unprotected receptive or insertive anal intercourse.

  Additionally, many transgender women reported high levels of alcohol and substance use. These substances can affect judgment and lead to unsafe sexual practices, which can increase HIV risk.

  The few studies examining HIV risk behaviors among transgender men suggest some have multiple male sex partners and engage in unprotected receptive anal or vaginal intercourse with men; however, no studies have reported links between these behaviors and HIV infection among transgender men. Nonetheless, these are established HIV risk behaviors in other populations.

- **Discrimination and social stigma** can hinder access to education, employment, and housing opportunities. In a study conducted in San Francisco, transgender people were more likely than MSM or heterosexual women to live in transient housing and have completed fewer years of education. Discrimination may help explain why transgender people who experience significant economic difficulties often pursue high-risk activities, including commercial sex work, to meet their basic survival needs. Social stigma also may explain why some transgender people engage in unprotected receptive intercourse with their sex partners. Qualitative data suggest that some transgender people who fear sex partner rejection or need their gender affirmed through sex may engage in unprotected receptive intercourse. High rates of depression, emotional distress, loneliness, and social isolation have been linked to suicidal thoughts and suicide attempts by transgender people. Therefore, interventions that address multiple co-occurring, syndemic public health problems—including substance use, poor mental health, violence and victimization, discrimination, and economic hardship—should be developed and evaluated for transgender people.

- **Health care provider insensitivity** to transgender identity or sexuality can be a barrier for HIV-infected transgender people seeking health care. Although research shows a similar proportion of HIV-positive transgender women have health insurance coverage as compared with other infected people who are not transgender, HIV-positive transgender women were less likely to be on antiretroviral therapy.

- **Additional research is needed to identify factors that prevent HIV in this population.** Several behavioral HIV prevention interventions developed for transgender people have been reported, generally involving relatively small samples comprised entirely or primarily of transgender women. Most have shown at least modest reductions in HIV risk behaviors, such as fewer sex partners and/or reducing unprotected anal sex acts, although none have involved a control group.

What CDC Is Doing

CDC recognizes that accurate information is key to understanding the HIV epidemic, public health needs, and gaps in services among all people at risk for HIV infection.

- In response to recommendations for collecting data from transgender people, CDC is currently revising the national system for reporting HIV cases to capture sex assigned at birth and current gender identity. This will improve the likelihood of accurately identifying diagnoses of HIV infection among transgender women and men.
- CDC is developing an HIV-related behavioral survey to monitor current HIV-related risk behaviors and prevention experiences among transgender women.
- CDC is currently collecting information on gender identity in its HIV testing programs.
- To respond to a shortage of proven behavioral HIV prevention interventions for the transgender community, CDC funded researchers to develop ground-breaking interventions for transgender people. Data from this research will be available later in 2011.
- CDC has funded organizations to adapt proven behavioral HIV prevention interventions for use with transgender people. Adapted curricula and supporting materials and technical assistance for implementing agencies are available.
- CDC-funded capacity building assistance (CBA) providers help community-based organizations (CBOs) serving transgender people to enhance structural interventions such as condom distribution, community mobilization, HIV testing, and coordinated referral networks and service integration.
- YMSM and YTransgender CBO Project — CDC currently funds prevention programs for transgender youth of color through the Prevention Program Branch.

Injustice at Every Turn

A Report of the National Transgender Discrimination Survey

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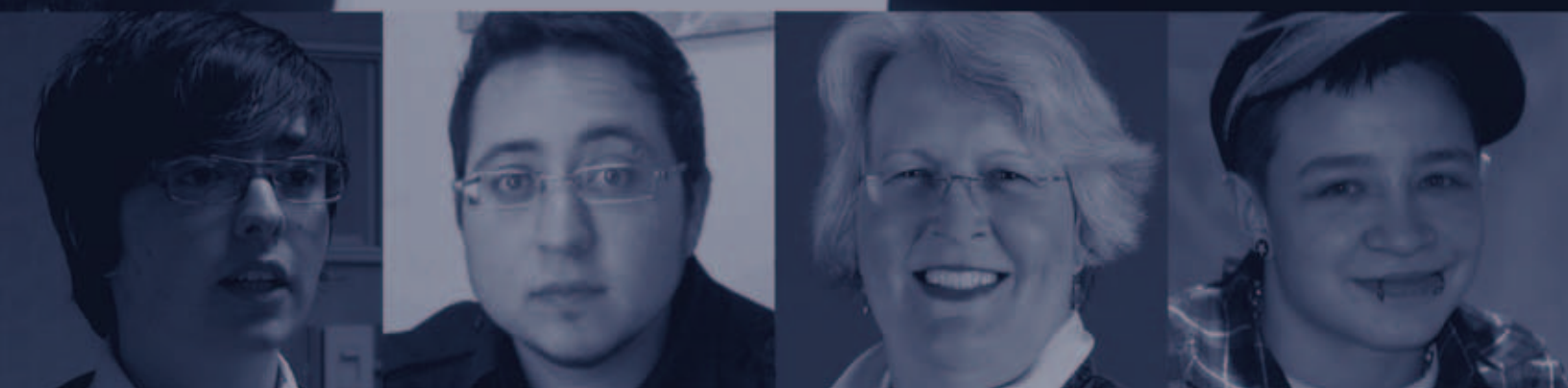
National Gay and Lesbian Task Force



HEALTH

Access to health care is a fundamental human right that is regularly denied to transgender and gender non-conforming people.

Transgender and gender non-conforming people frequently experience discrimination when accessing health care, from disrespect and harassment to violence and outright denial of service. Participants in our study reported barriers to care whether seeking preventive medicine, routine and emergency care, or transgender-related services. These realities, combined with widespread provider ignorance about the health needs of transgender and gender non-conforming people, deter them from seeking and receiving quality health care.

Our data consistently show that racial bias presents a sizable additional risk of discrimination for transgender and gender non-conforming people of color in virtually every major area of the study, making their health care access and outcomes dramatically worse.

KEY FINDINGS IN HEALTH

- Survey participants reported that when they were sick or injured, they **postponed medical care** due to discrimination (28%) or inability to afford it (48%).
- Respondents faced **serious hurdles to accessing health care**, including:
  - **Refusal of care**: 19% of our sample reported being refused care due to their transgender or gender non-conforming status, with even higher numbers among people of color in the survey.
  - **Harassment and violence in medical settings**: 28% of respondents were subjected to harassment in medical settings and 2% were victims of violence in doctor's office.
  - **Lack of provider knowledge**: 50% of the sample reported having to teach their medical providers about transgender care.
- The **majority of survey participants have accessed some form of transition-related medical care** despite the barriers; the majority reported wanting to have some type of surgery but have not had any surgeries yet.
- **If medical providers were aware of the patient's transgender status, the likelihood of that person experiencing discrimination increased**.
- Respondents reported **over four times the national average of HIV infection**, 2.64% in our sample compared to .6% in the general population, with rates for transgender women at 4.28%, and with those who are unemployed (4.67%) or who have done sex work (15.32%) even higher.[1]
- Over a quarter of the respondents **misused drugs or alcohol specifically to cope with the mistreatment** they faced due to their gender identity or expression.
- A staggering **41% of respondents reported attempting suicide** compared to 1.6% of the general population, with unemployment, bullying in school, low household income and sexual and physical associated with even higher rates.

Access to Healthcare

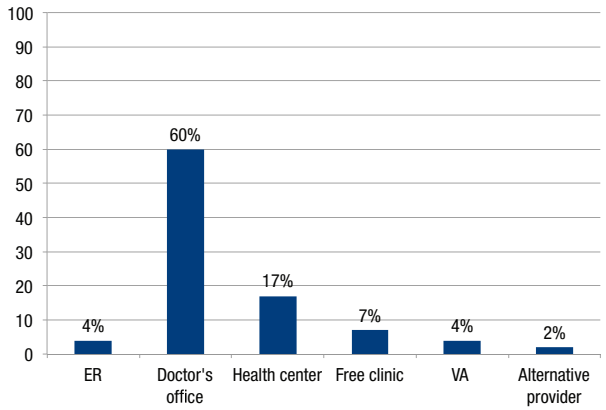
HEALTH CARE SETTINGS

A majority of study participants sought care ("when you are sick or need advice about your health") through a doctor's office (60%); however a sizable minority used health centers and clinics (28%). Four percent (4%) of respondents primarily used emergency rooms for care. Several studies have shown that individuals who use emergency rooms for primary care experience more adverse health outcomes than those who regularly see a primary physician.[2] Factors that correlated with increased use of emergency rooms (ERs) among our respondents were:

- Race—17% of African-Americans used ERs for primary care, as did 8% of Latino/a respondents;
- Household income—8% of respondents earning under $10,000 per year used ERs for primary care;
- Employment status—10% of unemployed respondents and 7% of those who said they had lost their jobs due to bias used ERs for primary care;
- Education—13% of those with less than a high school diploma used ERs for primary care.

Visual conformers and those who had identity documents that matched their presentation had high rates of using doctor's offices for their care.

Primary Source of Medical Care for Respondents



Health Care Experiences

DISCRIMINATION BY MEDICAL PROVIDERS

Denial of health care and multiple barriers to care are commonplace in the lives of transgender and gender non-conforming people. Respondents in our study seeking health care were denied equal treatment in doctor's offices and hospitals (24%), emergency rooms (13%), mental health clinics (11%), by EMTs (5%) and in drug treatment programs (3%).[3] Female-to-male respondents reported higher rates of unequal treatment than male-to-female respondents. Latino/a respondents reported the highest rate of unequal treatment of any racial category (32% by a doctor or hospital and 19% in both emergency rooms and mental health clinics).

19% of our sample reported being refused care altogether, due to their gender identity or expression, with even higher numbers among people of color in the survey.

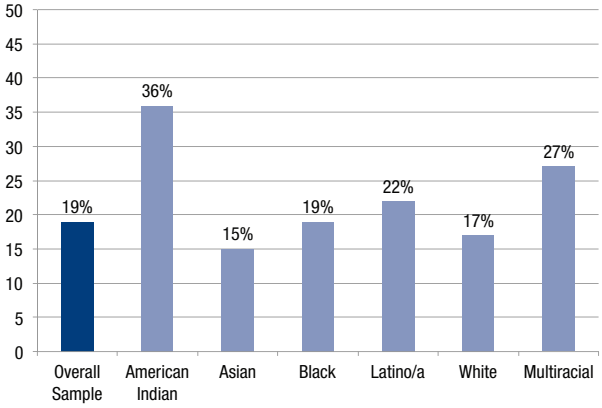
We also asked whether respondents had been ***denied service altogether*** by doctors and other providers.[4] Nineteen percent (19%) had been refused treatment by a doctor or other provider because of their transgender or gender non-conforming status.

Twenty-four percent (24%) of transgender women reported having been refused treatment altogether and 20% of transgender men did. Respondents who reported they had lost jobs due to bias (36%); American Indians (36%); those who worked in the underground economy (30%); those on public insurance (28%); and those who transitioned (25%) experienced high occurrence of refusal to treat.

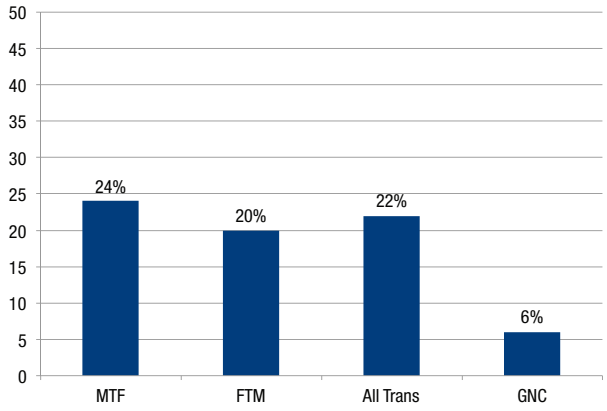
"After an accident on ice, I was left untreated in the ER for two hours when they found my breasts under my bra while I was dressed outwardly as male."

"I have been refused emergency room treatment even when delivered to the hospital by ambulance with numerous broken bones and wounds."

Refusal to Provide Medical Care by Race



Refusal to Provide Care by Gender Identity/Expression



"I have had general practitioners refuse to accept me as a patient on the basis of having a history of gender identity disorder."

VIOLENCE AND HARASSMENT WHEN SEEKING MEDICAL TREATMENT

Doctors' offices, hospitals, and other sources of care were often unsafe spaces for study participants. Over one-quarter of respondents (28%) reported verbal harassment in a doctor's office, emergency room or other medical setting and 2% of the respondents reported being physically attacked in a doctor's office.

2% of respondents reported being physically attacked in a doctor's office.

28% reported being verbally harassed in a medical setting.

Those particularly vulnerable to physical attack in doctors' offices and hospitals include those who have lost their jobs (6%); African-Americans (6%); those who done sex work, drug sales or other work in the underground economy (6%); those who transitioned before they were 18 (5%); and those who are undocumented non-citizens (4%).

In emergency rooms, 1% reported attack. Those more vulnerable to attack include those who are undocumented (6%); those who have worked in the underground economy (5%); those who lost their jobs (4%); and Asian respondents (4%). Obviously, harassment and physical attacks have a deterrent effect on patients seeking additional care and impact the wider community as information about such abuses circulates.

"My experiences in dealing with hospital personnel after my rape was not pleasant and lacked a lot of sensitivity to trans issues."

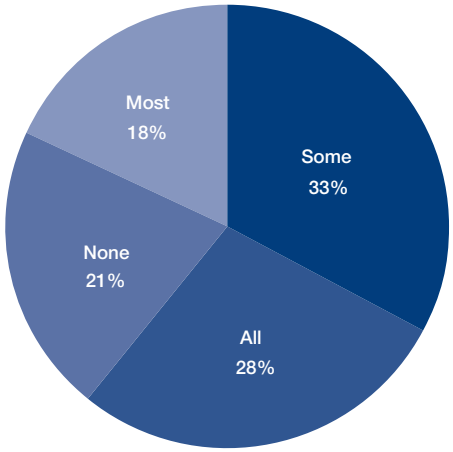
"When I tried to kill myself and was taken to a suicide center, I was made fun of by staff and treated roughly."

"I was forced to have a pelvic exam by a doctor when I went in for a sore throat. The doctor invited others to look at me while he examined me and talked to them about my genitals."

OUTNESS AND DISCRIMINATION

Twenty-eight percent (28%) of respondents said they were out to all their medical providers. Eighteen percent (18%) said they were out to most, 33% said some or a few, and 21% were out to none.

When Seeking Medical Care, How Many People Know or Believe You Are Transgender or Gender Non-Conforming?



Doctors can provide more effective care when they have all medically relevant information about their patients. Unfortunately, our data shows that doctors' knowledge of a patient's transgender status increases the likelihood of discrimination and abuse. Medical professionals' awareness of their patient's transgender status ***increased experiences of discrimination*** among study participants up to eight percentage points depending on the setting:

- **Denied service altogether:** 23% of those who were out or mostly out to medical providers compared to 15% of those who were not out or partly out
- **Harassment in ambulance or by EMT**: 8% of those who were out or mostly out to medical providers compared with 5% of those who were not out or partly out
- **Physically attacked or assaulted in a hospital**: 2% of those who were out or mostly out to medical providers compared with 1% of those who were not out or partly out

"I have been harassed and physically assaulted on the street. One time, I didn't go the hospital until I went home, changed [out of feminine] clothes, and then went to the emergency room in male mode. I had a broken collar bone as a result of that attack."

"I rarely tell doctors of my gender identity. It just seems so hard to explain what "genderqueer" means in a short doctor's appointment. I also am reluctant to take the risk of discrimination; I need to be healthy more than I need to be out to my doctors. I hate making this compromise. But I'm not quite that brave yet."

"Denial of health care by doctors is the most pressing problem for me. Finding doctors that will treat, will prescribe, and will even look at you like a human being rather than a thing has been problematic. Have been denied care by doctors and major hospitals so much that I now use only urgent care physician assistants, and I never reveal my gender history."

MEDICAL PROVIDERS' LACK OF KNOWLEDGE

50% of the sample reported having to teach their medical providers about transgender care.

When respondents saw medical providers, including doctors, they often encountered ignorance about basic aspects of transgender health and found themselves required to "teach my provider" to obtain appropriate care. Fully 50% of study respondents reported having to teach providers about some aspect of their health needs; those who reported "teaching" most often include transgender men (62%), those who have transitioned (61%) and those on public insurance (56%).

"I have several health issues and have been refused care by one doctor who 'suggested' that I go someplace else because she could not treat me since she 'did not know anything about transgender people.' "

POSTPONEMENT OF NECESSARY AND PREVENTIVE MEDICAL CARE

One fourth of study participants reported delaying needed care because of disrespect and discrimination from medical providers.

We asked respondents whether they postponed or did not try to get two types of health care: preventive care "like checkups" and necessary care "when sick or injured." We found that many postponed care because they ***could not afford it*** and many postponed care because of ***discrimination and disrespect from providers***.

A large number of study participants postponed necessary medical care due to inability to afford it, whether seeking care when sick or injured (48%), or pursuing preventive care (50%). Transgender men reported postponing any care due to inability to afford it at higher rates (55%) than transgender women (49%).

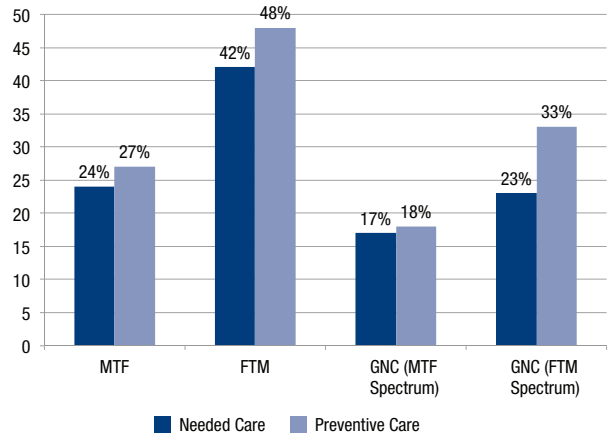
Insurance was a real factor in delayed care: those who have private insurance were much less likely to postpone care because of inability to afford it when sick or injured (37%) than those with public (46%) or no insurance who postponed care (86%).

In terms of preventive care, those without insurance reported delaying care due to inability to afford it much more frequently (88%) than those with private insurance (39%) or public insurance (44%). Failing to obtain preventive care is known to lead to poor long-term health outcomes.

Due to discrimination and disrespect, 28% postponed or avoided medical treatment when they were sick or injured and 33% delayed or did not try to get preventive health care. Female-to-male transgender respondents reported postponing care due to discrimination and disrespect at a much higher frequency (42%, sick/injured; 48% preventive) than male-to-female transgender respondents (24%, sick/injured; 27% preventive). Those with the highest rates of postponing care when sick/injured included those who have lost a job due to bias (45%) and those who have done sex work, sold drugs, or done other work in the underground economy for income (45%). Twenty-nine percent (29%) of respondents who were "out" or "mostly out" to medical providers reported they had delayed care when ill and 33% postponed or avoided preventive care because of discrimination by providers.

"The transition and health care has been expensive, all at a time where my main source of income (my law practice) deteriorated. I have exhausted my savings and the equity from selling my home just to pay medical and living expenses."

Postponement Due to Discrimination by Providers



ACCESS TO INSURANCE

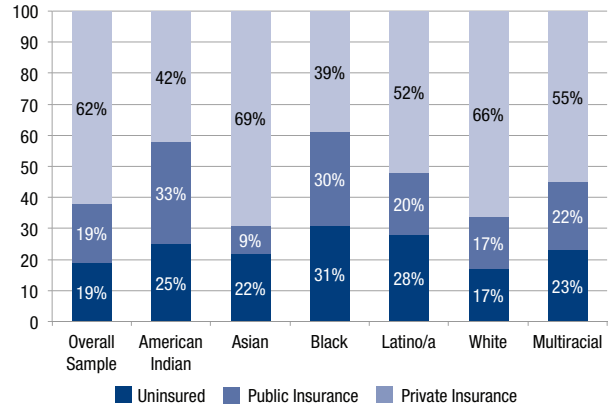
Study participants were less likely than the general population to have health insurance, more likely to be covered by public programs such as Medicare or Medicaid, and less likely to be insured by an employer.

Nineteen percent (19%) of the sample lacked any health insurance compared to 17% of the general population.[5] Fifty-one percent (51%) had employer-based coverage compared to 58% of the general population.[6]

African-American respondents had the worst health insurance coverage of any racial category: 39% reported private coverage and 30% public. Thirty-one percent (31%) of Black respondents reported being uninsured; by contrast 66% of white respondents reported private insurance, 17% public insurance and 17%

uninsured. In the general population, 68% have private insurance and 28% have public insurance.[7]

Health Insurance by Race

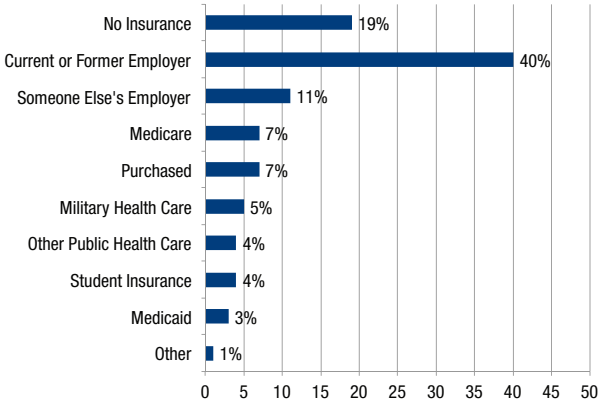


Undocumented non-citizens had very low rates of coverage: 26% reported private insurance, 37% public insurance, and 36% no insurance. The South was the worst region for coverage where 59% of respondents reported private insurance, 17% public insurance and 25% no insurance.

Transgender women reported private insurance at 54%, public insurance at 24% and 22% were uninsured. Transgender men reported private insurance at 68%, public insurance at 13% and 19% with no insurance. Transgender respondents, overall, reported private insurance at 60%, public insurance at 20% and 20% had no insurance. Gender non-conforming respondents were insured at higher rates than their transgender counterparts, with 73% reporting private insurance, 11% public insurance, and 17% uninsured.

"I have been living with excruciating pain in my ovaries because I can't find a doctor who will examine my reproductive organs." (from a transgender man)

Source of Insurance



Transition-related Care

The majority of survey participants have accessed some form of transition-related medical care despite the barriers.

Most survey respondents had sought or accessed some form of transition-related care. Counseling and hormone treatment were notably more utilized than any surgical procedures, although the majority reported wanting to "someday" be able to have surgery. The high costs of gender-related surgeries and their exclusion from most health insurance plans render these life-changing (in some cases, life-saving) and medically necessary procedures inaccessible to most transgender people.

Throughout this section, we focus primarily on transgender people rather than on gender non-conforming people, though they too may also desire and sometimes use various forms of gender-related medical care.

The World Professional Association for Transgender Health (WPATH) publishes Standards of Care[8] which are guidelines for mental health, medical and surgical professionals on the current consensus for providing assistance to patients who seek transition-related care. They are intended to be flexible to assist professionals and their patients in determining what is appropriate for each individual. The Standards of Care are a useful resource in understanding the commonly experienced pathways through transition-related care.

"My choices for health coverage at my employer all exclude any treatment for transgender issues, even though they cover things like hormones for other people."

COUNSELING

Counseling often plays an important role in transition. Because of the WPATH Standards of Care, medical providers often require a letter from a qualified counselor stating that the patient is ready for transition-related medical care; transgender people may seek out counseling for that purpose. Counseling may also play a role in assisting with the social aspects of transition, especially in dealing with discrimination and family rejection.

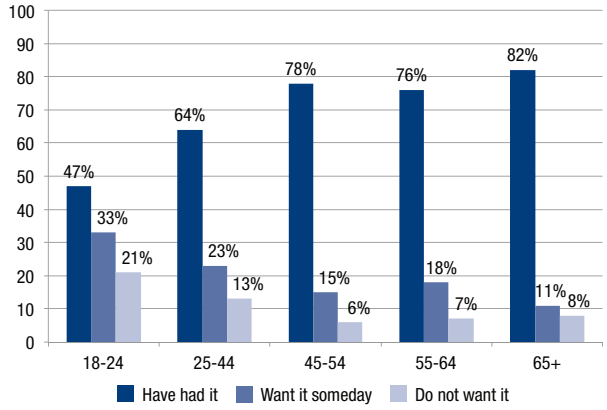
Seventy-five percent (75%) of respondents received counseling related to their gender identity and an additional 14% hoped to receive it someday. Only 11% of the overall sample did not want it. Those who identified as transgender were much more likely to have had counseling (84%) than those who are gender non-conforming (48%). Eighty-nine percent (89%) of those who medically transitioned have received counseling, as have 91% of those who had some type of surgery.

Part of counseling can involve receiving a gender-related mental health diagnosis such as "Gender Identity Disorder." Many doctors require this diagnosis before providing hormones or surgical treatment, but the diagnosis itself is widely criticized for categorizing naturally occurring gender variance as pathological.[9] Fifty-percent (50%) of study participants have received a gender-related mental health diagnosis. Transgender women reported a higher rate of diagnosis (68%) than transgender men (56%); and transgender-identified participants had a substantially higher rate of diagnosis (63%) than gender non-conforming respondents (11%).

HORMONE THERAPY

Sixty-two percent (62%) of respondents have had hormone therapy, with the likelihood increasing with age; an additional 23% hope to have it in the future. Transgender-identified respondents accessed hormonal therapy (76%) at much higher rates than their gender non-conforming peers, with transgender women more likely to have accessed hormone therapy (80%) than transgender men (69%). Almost all respondents who reported undertaking transition-related surgeries also reported receiving hormone therapy (93%).

Hormone Therapy by Age of Respondent

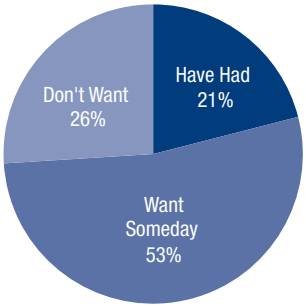


"I can no longer afford health care of any kind. I am fully transitioned and thus reliant upon estradiol as my body produces neither estrogens nor androgens in sufficient quantity. I am unable to go to the doctor for my prescriptions, and thus have been unable to buy my hormones for over one year. Thus I watch my hair falling out, my nails dissolve and am weak and tired like a far older lady than I am."

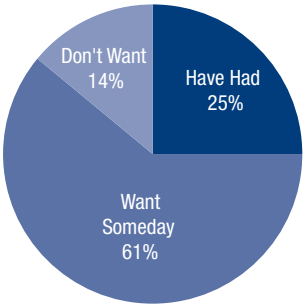
SURGERY—MALE-TO-FEMALE

Transgender women may elect to undertake a variety of surgeries, including breast augmentation, orchiectomy (removal of testes), vaginoplasty (creation of a vagina and/or removal of the penis), and facial feminization surgeries. We asked respondents to report on whether they had, or wanted, breast augmentation surgery, orchiectomies and vaginoplasties. As the charts below show, most transgender women reported wanting or having these surgeries. In addition, 17% reported having had facial surgery.[10] However, it is impossible to know how many others would desire or utilize surgery if it was more financially accessible.

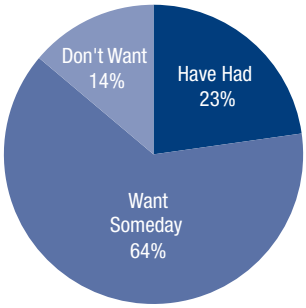
MTF Breast Augmentation Surgery



MTF Orchiectomy



MTF Vaginoplasty

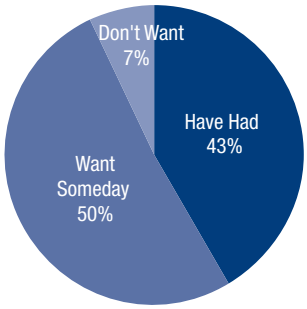


"I cannot afford gender reassignment surgery which is crucial to my mental well being and thoughts of suicide are always present."

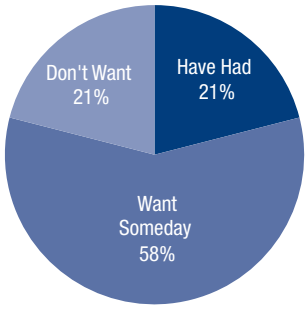
SURGERY—FEMALE-TO-MALE

Transgender men may elect to undertake a variety of surgeries, including chest reconstruction, hysterectomy, metoidioplasty and other genital surgeries. We asked respondents to report on chest surgery; hysterectomy; metoidioplasty, which releases the clitoris; surgeries that create testes; and phalloplasty, which surgically creates a penis and testes. The majority of FTM transgender-identified respondents wanted to have, or have already had, chest surgery and a hysterectomy. However, when it came to genital surgeries, very few reported having such surgeries; a slim majority (53%) reported desiring other genital surgery such as metoidioplasty in addition to the 3% that have had it; and one-quarter (27%) wanted to have a phalloplasty in addition to the 1% who have had it. It is impossible to know how these rates would change if these surgeries were more financially accessible.

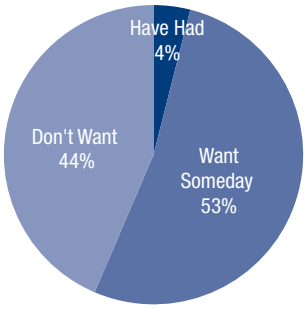
FTM Chest Surgery



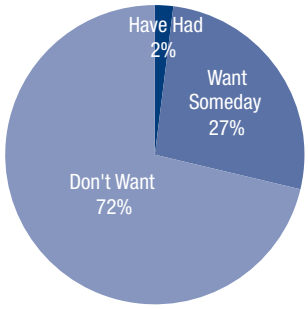
FTM Hysterectomy



FTM Metoidioplasty/ Creation of Testes



FTM Phalloplasty



"I have also have had several bouts with depression and anxiety disorders and once ended up in the emergency room for depression. I still bounce in and out of depression due to not being able to get the appropriate surgical procedures."

Health Vulnerabilities

Survey participants reported poorer health outcomes than the general population in a variety of critical health areas.

PHYSICAL VIOLENCE AND SEXUAL ASSAULT

"As a child because I acted "girly," I was a victim of severe child abuse, and was sexually assaulted. I avoided transitioning until I came to the point of suicide."

In questions related to experiences in educational settings, at work, in interactions with police and with family members, at homeless shelters, accessing public accommodations, and in jails and prisons, respondents were asked about physical violence or sexual violence, or both, committed against them because of their gender identity/expression. There was no *general question* asked about whether respondents had ever experienced any bias-motivated violence, and further, there was no question that asked to report on violence that was not *specifically motivated* by anti-transgender bias.

Twenty-six percent (26%) of respondents had been physically assaulted in at least one of these contexts because they were transgender or gender non-conforming. Ten percent (10%) of respondents were sexually assaulted due to this bias.

Having been physically or sexually assaulted aligned with a range of other negative outcomes, as described below in each relevant section.

HIV

Respondents reported over four times the national average of HIV infection.

Respondents reported an HIV infection rate of 2.64%,[11] over four times the rate of HIV infection in the general United States adult population (0.6%) as reported by the United Nations Programme on HIV/AIDS and the World Health Organization.[12] People of color reported HIV infection at substantially higher rates: 24.90% of African-Americans, 10.92% of Latino/as, 7.04% of American Indians, and 3.70% of Asian-Americans in the study reported being HIV positive. This compares with national rates of 2.4% for African Americans, .08% Latino/as, and .01% Asian Americans.[13] Non-U.S. citizens in our sample reported more than twice the rate of HIV infection of U.S. citizens (2.41%), with documented non-citizens at 7.84% and undocumented at 6.96%.

Doing sex work for income clearly was a major risk factor, with 61% of respondents who were HIV positive reporting they had done sex work for income. To consider this from a different angle, of all the people in our sample who had done sex work, 15.32% reported being HIV positive.

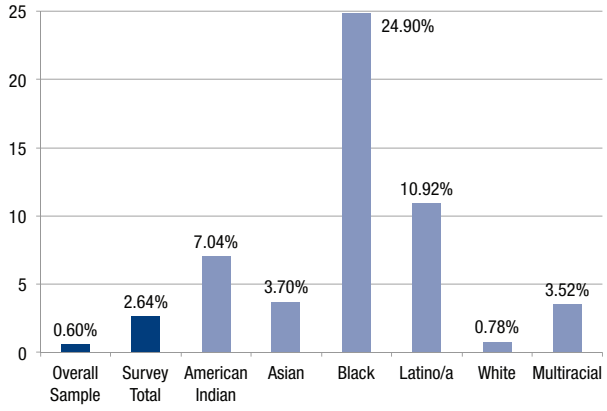
Among survey participants, 88% of those who reported being HIV positive identified as either MTF or gender non-conforming on the male-to-female spectrum. The reported rate of HIV infection for the MTF transgender respondents was 4.28%. The reported rate of HIV infection for FTM respondents was .51%, lower than the national average.

Other categories that reported substantially higher HIV rates than the sample as a whole were:

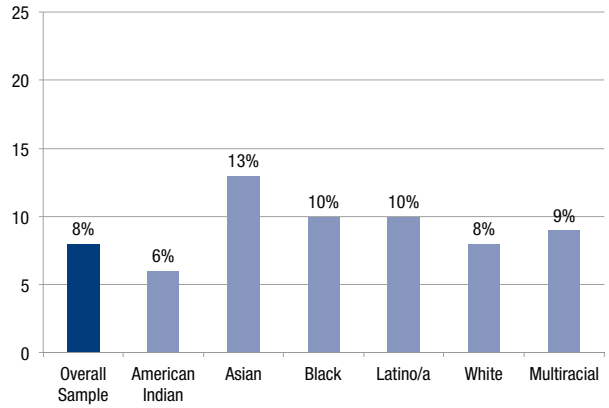
- Those without a high-school diploma (13.49%)
- Those who had been sexually assaulted due to bias (10.13%)
- Those with household income below $10,000 a year (6.40%)
- Those who had lost a job due to bias (4.59%) or reported being unemployed (4.67%)

Eight percent (8%) of our sample reported that they did not know their HIV status. Transgender women and transgender men had equal rates of not knowing, both 8%, with transgender respondents also at 8% and gender non-conforming respondents at 9%. Those most likely not to know their HIV status include undocumented non-citizens (17%), those with household incomes under $10,000/year (14%), and those with lower educational attainment (those with no high school diploma and high school diploma only, both at 13%).With regard to race, Asian respondents were least likely to know their status (13%).

HIV Infection By Race, Compared to U.S. General Population



HIV Status Unknown By Race



DRUG AND ALCOHOL USE

The National Institutes of Health (NIH) estimate that 7.3% of the general public abuses or is dependent on alcohol, while 1.7% abuses or is dependent on non-prescription drugs.[14] Eight percent (8%) of study participants reported currently using alcohol or drugs specifically to cope with the mistreatment that they received as a result of being transgender or gender non-conforming, while 18% said they had done so in the past but do not currently. We did not ask about general use of alcohol and drugs, only usage which the respondents described as a coping strategy for dealing with the mistreatment they face as transgender or gender non-conforming persons.

26% use or have used alcohol and drugs to cope with the impacts of discrimination.

Doing sex work, drug sales, and other work in the underground economy for income more than doubles the risk of alcohol or drug use because of mistreatment, with 19% of these respondents currently using alcohol and/or drugs while 36% reported that they had done so in the past. Those who have been the physically attacked due to bias also had a higher rate of current alcohol and drug misuse (15%) as did those who have been sexually assaulted due to bias (16%). Also at elevated risk were those who had lost a job due to discrimination; 12% reported currently using drugs and alcohol, while 28% have done so in the past.

"I do not use drugs but my drinking has increased over the past 3 years due to stress and loneliness."

"When I started coming out, I stopped the drinking and stopped the depression medicines. When I started living full time in my real gender, I blossomed into an outgoing, loving, giving person."

Alcohol and drug use decreased by age among our participants, as they did in studies of the general population,[15] with those 65 years and above reporting less than half the rate of use (4%) of those who are the 18-44 age range (9%). This contrasts with studies of LGBT populations that show a less dramatic decrease in use over the life cycle;[16] however, because our study only asked about use connected to mistreatment, the comparisons with both the general population and LGBT studies are not precise.

SMOKING

Thirty percent (30%) of our sample reported smoking daily or occasionally, compared to 20.6% of U.S. adults.[17] Studies of LGBT adults show similar rates to those in our study, with elevated rates of 1.1-2.4 times that of the general population,[18] and a 2004 California study found a 30.7% smoking rate for transgender people.[19] In the general population, men smoke at higher rates than women, but in LGBT studies, women smoke at higher rates than men. Our sample resembled the LGBT data regarding elevated smoking levels but differed in that more men than women in our sample smoke, a pattern that is closer to that of the general population. When asked if they would "like to quit," 70% of smokers in the study selected yes.

Comparative Smoking Rates from Other Studies,[20] Compared to Our Study

	General Population	Lesbian and Gay	Bisexual	Our Sample
Men	23.1%	26.5-30.9%	29.5-38.1%	33%
Women	18.3%	22.3-26%	30.9-39.1%	29%

Visual conformers were less likely to be current smokers (27%) than visual non-conformers (37%), suggesting that the stress caused by the additional mistreatment that visual non-conformers face may be involved in the development of an addiction to nicotine. Similarly, those who have been physically assaulted due to bias (40%) and sexually assaulted due to bias (45%) have higher smoking rates than their peers who were not assaulted.

SUICIDE ATTEMPTS

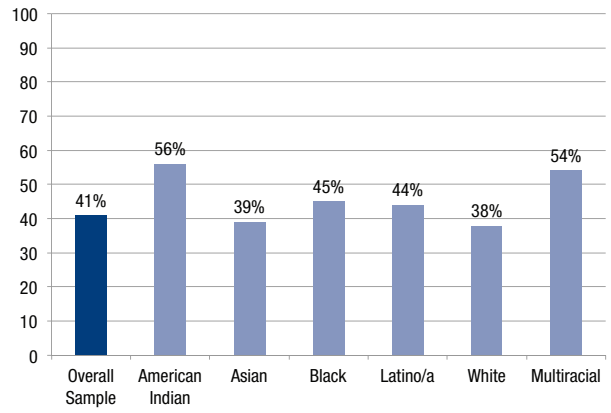
When asked "have you ever attempted suicide?" 41% of respondents answered yes. According to government health estimates, five million, or 1.6% of currently living Americans have attempted suicide in the course of their lives.[21] Our study asked if respondents had ever attempted suicide while most federal studies refer to suicide attempts within the last year; accordingly it is difficult to compare our numbers with other studies. Regardless, our findings show a shockingly high rate of suicidality.

41% of respondents reported attempting suicide.

The National Institute for Mental Health (NIMH) reports that most suicide attempts are signs of extreme distress, with risk factors including precipitating events such as job loss, economic crises, and loss of functioning.[22] Given that respondents in this study reported loss in nearly every major life area, from employment to housing to family life, the suicide statistics reported here cry out for further research on the connection between the consequences of bias in the lives of transgender and gender non-conforming people and suicide attempts.[23]

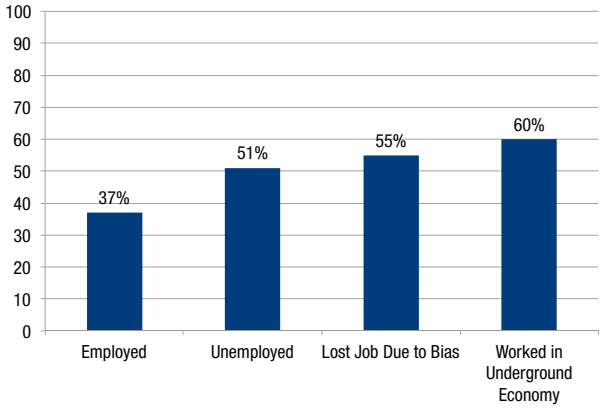
NIMH also reports that generally African-Americans, Latino/as and Asians have much lower suicide rates than whites and American Indians; our sample showed a different pattern of risk for suicide by race, with Black and Latino/a respondents showing dramatically elevated rates in comparison to their rates in the general population.

Suicide Attempt by Race



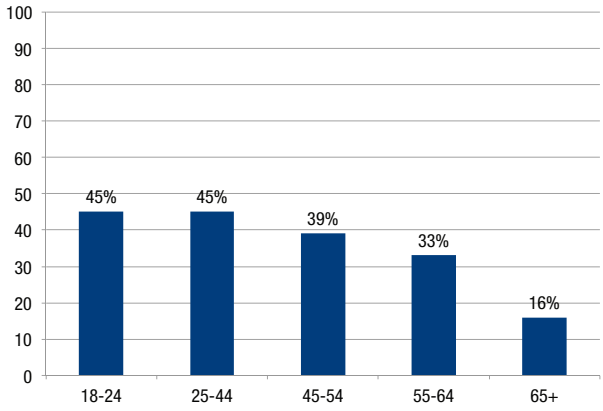
Respondents' work status and experiences of discrimination in employment also had a sizable impact on their likelihood of having attempted suicide.

Suicide Attempt by Employment



In terms of age group risk, the highest rates of suicide attempts in this study were reported among those in the 18-24 age group (45%) and 25-44 age group (45%), with only 16% of those over 65 reporting a suicide attempt. These rates are inverse to the general population, which shows a higher incidence of attempts among older Americans than youth.[24]

Suicide Attempts by Age



Our questionnaire did not ask at what age the respondents made suicide attempts and therefore it is difficult to draw conclusions about the risk of suicide over their life spans. However, there are a number of attributes that align with an increased rate of attempted suicide. High risk groups include visual non-conformers (44%) and those who are generally out about their transgender status (44%). Those who have medically transitioned (45%) and surgically transitioned (43%) have higher rates of attempted suicide than those who have not (34% and 39% respectively).

Over half of those bullied, harassed, assaulted, or expelled due to bias in school attempt suicide.

Those who were bullied, harassed, assaulted, or expelled because they were transgender or gender non-conforming in school (at any school level) reported elevated levels of suicide attempts (51% compared with 41% of our sample as a whole). Most notably, suicide attempt rates rise dramatically when teachers were the reported perpetrators: 59% for those harassed or bullied by teachers, 76% among those who were physically assaulted by teachers and 69% among those who were sexually assaulted by teachers. These numbers speak to the urgency of ending violence and harassment of transgender students by both their peers and their teachers.

Education and household income both align with suicide rates, with those earning $10,000 annually or less at extremely high risk (54%), while those making more than $100,000 are at comparatively lower risk (26%), while still tremendously higher than the general population. Those who have not completed college attempted suicide at higher rates (48% among those with no high school diploma, 49% for those with a high school diploma only, and 48% for those with some college education) while those have completed college (33%) or graduate school (31%) have lower rates.

Those who had survived violence perpetrated against them because they were transgender or gender non-conforming were at very high risk; 61% of physical assault survivors reported a suicide attempt, while sexual assault survivors reported an attempt rate of 64%.

"My suicide attempt had a lot to do with the fact that I felt hopeless and alone in regards to my gender identity."

CONCLUSIONS FOR HEALTH

Respondents reported serious barriers to health care and outrageous frequencies of anti-transgender bias in care, from disrespect to refusal of care, from verbal harassment to physical and sexual abuse. Transgender people of color and low-income respondents faced substantially elevated risk of abuse, refusal of care, and poor health outcomes than the sample as a whole.

The data gathered here speak to a compelling need to examine the connection between multiple incidences of discrimination, harassment and abuse faced by our respondents in the health care system and the high risk for poor health outcomes. Additionally, our data suggest that discriminatory events are commonplace in the daily lives of transgender people and that this has a cumulative impact—from losing a job because of bias to losing health insurance; from experiencing health provider abuse to avoiding health care; from long-term unemployment to turning to work on the streets. The collective impact of these events exposed our respondents to increased risk for HIV infection, smoking, drug/alcohol use, and suicide attempts.

It is important to note that the traumatic impact of discrimination also has health care implications. Transgender people face violence in daily life; when this risk is compounded by the high rates of physical and sexual assault they face while accessing medical care, health care costs increase, both to treat the immediate trauma as well as ongoing physical and psychological issues that may be created.

As we have seen across a number of categories in the survey, the ability to work substantially impacts transgender health. In particular, those who have been fired due to anti-transgender bias and those who have done sex work, drug sales, or other work in the underground economy are much more likely to experience health risks that are shown to lead to poorer health outcomes.

Discrimination in the health care system presents major barriers to care for transgender people and yet a majority of our survey participants were able to access some transition-related care, with 75% receiving counseling and 62% obtaining hormones. Genital surgery, on the other hand, remains out of reach for a large majority, despite being desired by most respondents. This is one important reason why legal rights for transgender people must never be determined by surgical status.

"I saw a doctor in New York and told her how I wanted [chest surgery]. She looked at me sternly and said, 'I can't believe you are wasting my time. Do you know what your problem is? You just want to be a boy. You want to be a boy and that's never gonna happen so just do yourself a favor and get over it.' Then she left the room abruptly. I grabbed my things and bolted down the street, feeling like the biggest freak in the world."

RECOMMENDATIONS FOR HEALTH

- Anti-transgender bias in the medical profession and U.S. health care system has catastrophic consequences for transgender and gender non-conforming people. This study is a call to action for the medical profession:
  - The medical establishment should fully integrate transgender-sensitive care into its professional standards, and this must be part of a broader commitment to cultural competency around race, class, and age;
  - Doctors and other health care providers who harass, assault, or discriminate against transgender and gender non-conforming patients should be disciplined and held accountable according to the standards of their professions.
- Public and private insurance systems should cover transgender-related care; it is urgently needed and is essential to basic health care for transgender people.
- Ending violence against transgender people should be a public health priority, because of the direct and indirect negative effect it has on both victims and on the health care system that must treat them.
- Medical providers and policy makers should never base equal and respectful treatment and the attainment of appropriate government-issued identity documents on:
  - Whether an individual has obtained surgery, given that surgeries are financially inaccessible for large majorities of transgender people because they are rarely covered by either public or private insurance;
  - Whether an individual is able to afford or attain proof of citizenship or legal residency.
- Rates of HIV infection, attempted suicide, drug and alcohol abuse, and smoking among transgender and gender non-conforming people speak to the overwhelming need for:
  - Transgender-sensitive health education, health care, and recovery programs;
  - Transgender-specific prevention programs.
- Additional data about the health outcomes of transgender and gender non-conforming people is urgently needed:
  - Health studies and other surveys need to include gender identity as a demographic category;
  - Information about health risks, outcomes and needs must be sought specifically about transgender populations;
  - Transgender people should not be put in categories such as “men who have sex with men” (MSM) as transgender women consistently are and transgender men sometimes are. Separate categories should be created for transgender women and transgender men so HIV rates and other sexual health issues can be accurately tracked and researched.

Endnotes

1 HIV rates are presented with two decimal places for more accurate comparison with general population figures.

2 See for example P. Foraselli, C. DeAngelis, and A. Kaszuba, "Compliance with follow-up appointments generated in a pediatric emergency room, " *American Journal of Preventive Medicine*, 1, no. 3 (1985); V.T. Chande, S.E. Krug, and E.F. Warm, "Pediatric emergency department utilization habits: a consumer survey," *Pediatric Emergency Care*, 12, no. 1 (1996).

3 These results were based on question 30, which was prefaced by: "Based on being transgender/gender non-conforming, please check whether you have experienced any of the following in these public spaces," and asked respondents to indicate whether they had been "denied equal treatment or service" for each of the various locations.

4 These results were based on question 43, which was prefaced by: "Because you are transgender/gender non-conforming, have you had any of the following experiences?" and asked respondents to indicate whether "a doctor or other provider refused to treat me because I am transgender/gender non-conforming."

5 U.S. Census Bureau, "Current Population Reports, Income, Poverty, and Health Insurance Coverage in the United States" (2008): http://www.census.gov/prod/2009pubs/p60-236.pdf. Data for those 18 and over were used.

6 U.S. Census Bureau, "Current Population Reports, Income, Poverty, and Health Insurance Coverage in the United States" (2008): http://www.census.gov/prod/2009pubs/p60-236.pdf. Data for those 18 and over were used.

7 U.S. Census Bureau, "Current Population Reports, Income, Poverty, and Health Insurance Coverage in the United States" (2008): http://www.census.gov/prod/2009pubs/p60-236.pdf. Data for those 18 and over were used.

8 World Professional Association of Transgender Health, "Standards of Care for Gender Identity Disorders, Sixth Version" (2001): http://www.wpath.org/documents2/socv6.pdf

9 The National Gay and Lesbian Task Force's statement on reform of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM) can be accessed at http://www.transgenderlaw.org/medicalhealthcare/NGLTF_DSM_Statement.pdf. The National Center for Transgender Equality's position may be found at http://transgenderequality.wordpress.com/wp-admin/post.php?post=264&action=edit

10 The facial feminization surgery rate was determined differently than the other surgery data. We determined the rate by looking at how many respondents reported spending a valid dollar amount in Question 45.

11 HIV rates are presented with two decimal places for closer comparison with general population figures.

12 United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization (WHO), "2007 AIDS Epidemic Update" (2007): http://data.unaids.org/pub/EPISlides/2007/2007_epiupdate_en.pdf

13 Henry J. Kaiser Family Foundation, "The HIV-AIDS Epidemic in the United States" (2007): http://www.kff.org/hivaids/upload/3029-071.pdf

14 U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, "Results from the 2008 National Survey on Drug Use and Health: National Findings" (2009): http://www.oas.samhsa.gov/nsduh/2k8nsduh/2k8Results.pdf

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16 National Institute on Alcohol and Alcoholism, "Sexual Orientation and Alcohol Use Disorders" (2005): http://pubs.niaaa.nih.gov/publications/social/Module10GSexualOrientation/Module10G.html

17 American Lung Association, "Smoking Out a Deadly Threat: Tobacco Use in the LGBT Community" (2010): http://www.lungusa.org/assets/documents/publications/lung-disease-data/lgbt-report.pdf

18 Review of literature aggregated in American Lung Association, "Smoking Out a Deadly Threat: Tobacco Use in the LGBT Community" (2010): http://www.lungusa.org/assets/documents/publications/lung-disease-data/lgbt-report.pdf

19 California Department of Health Services, "California Lesbians, Gays, Bisexuals, and Transgender (LGBT) Tobacco Use Survey — 2004" (2005): http://www.cdph.ca.gov/programs/tobacco/Documents/CTCP-LGBTTobaccoStudy.pdf

20 The general population, lesbian and gay, and bisexual data in this table is from California Department of Health Services, "California Lesbians, Gays, Bisexuals, and Transgender (LGBT) Tobacco Use Survey — 2004." The data on transgender persons is ours.

21 "U.S.A. Suicide: 2002 Official Final Data," prepared for the American Association of Suicidology by John L. McIntosh, Ph.D. Official data source: Kochanek, K.D., Murphy, S.L., Anderson, R.N., & Scott, C. (2004). Deaths: Final data for 2002. National Vital Statistics Reports, 53 (5). Hyattsville, MD: National Center for Health Statistics DHHS Publication No. (PHS) 2005-1120. Population figures source: table I, p.108. of the National Center for Health Statistics (Kochanek et al., 2004), see http://www.sprc.org/library/event_kit/2002datapgv1.pdf

22 U.S Department of Health and Human Services, National Institute of Mental Health, "Suicide in the U.S.: Statistics and Prevention" (2010): http://www.nimh.nih.gov/health/publications/suicide-in-the-us-statistics-and-prevention/index.shtml

23 American Foundation for Suicide Prevention, "Risk Factors for Suicide" (2010): http://www.afsp.org/index.cfm?fuseaction=home.viewPage&page_id=05147440-E24E-E376-BDF4BF8BA6444E76 According to the Substance Abuse and Mental Health Services Administration, adults who have had a major depressive episode—the leading risk factor for suicide—in the previous twelve months had an attempt rate of 10.4%.

24 U.S. Department of Health and Human Services, National Institute of Mental Health, "Suicide in the U.S.: Statistics and Prevention" (2010): http://www.nimh.nih.gov/health/publications/suicide-in-the-us-statistics-and-prevention/index.shtml

Infectious Disease News®

High HIV burden identified in transgender women

Baral S. *Lancet Infect Dis.* 2013;13:214-222.

February 26, 2013

Transgender women comprise a high burden population of HIV worldwide, according to data published in *The Lancet Infectious Diseases.*

"Transgender women have been either excluded or ignored in most HIV surveillance systems around the world, resulting in a limited understanding of the burden of HIV among this group," **Stefan Baral, MD, MPH,** director of the key populations programs in the Center for Public Health and Human Rights at Johns Hopkins School of Public Health, told *Infectious Disease News*. "However, where studied, transgender women carry among the highest burden of HIV of any population."

Stefan Baral

Baral and colleagues conducted a systematic review and meta-analysis of studies examining the HIV burden in transgender women. They compared the HIV burdens between transgender women and other adults in the country.

The analysis included data from 15 countries, all of which had male-predominant HIV epidemics. Worldwide, the HIV prevalence among 11,066 transgender women was 19.1% (95% CI, 17.4-20.7). In low-income and middle-income countries, the HIV prevalence among 7,197 transgender women was 17.7% (95% CI, 15.6-19.8). Among the 3,869 transgender women from high-income countries, the HIV prevalence was 21.6% (95% CI, 18.8-24.3).

Compared with all adults in the 15 countries, the OR of transgender women having HIV was 48.8 (95% CI, 21.2-76.3). This did not differ between high-income and low-income and middle-income countries.

"The results were surprising in terms of the magnitude of the increased odds — nearly 50 times — of transgender women having HIV compared to other adults of reproductive age," Baral said. "These data should stimulate interest in characterizing the burden of HIV and associated risk factors for transgender women across the world. In addition, these data suggest that studies need to be developed for transgender women specifically, rather than accruing them as a subpopulation of men who have sex with men."

Baral said the study results have raised interest in further characterizing the risk factors for HIV infection among these women, with a focus on higher order risk factors such as stigma limiting the uptake of services. In addition, the researchers want to characterize and evaluate appropriate combination HIV prevention approaches targeted to transgender women, including biomedical, behavioral and structural approaches.

Disclosure: Baral reports no relevant financial disclosures.

AIDS 2012: HIV in Transgender Communities

July 25, 2012, by *San Francisco AIDS Foundation*

Joanne Keatley speaks at AIDS 2012 (photo: Ryan Rayburn)

Up to 68% of transgender women in North America are living with HIV—a staggering number presented Tuesday at AIDS 2012 by Joanne Keatley, director of the *Center for Excellence for Transgender Health* at the University of California, San Francisco. HIV prevalence for other regions is similarly shocking: 27.6% to 37.1% for transgender women in South America, 11.5% to 57% in Europe, and 2% to 45.2% in South Asia, Keatley shared. Wide ranges in HIV prevalence estimates testify to the patchy data available on this highly stigmatized and marginalized population. (*See a description and summary of this bridging session here.*)

“Transgender” is a term for someone whose gender identity—self-expression as female, male, or something in between—doesn’t match their culture’s expectations. Trans people highlight the distinction between biological “sex,” which is all about the reproductive bits you’re born with, and “gender,” referring to the range of ways to express femininity and/or masculinity. (For an in-depth exploration of transgender health, HIV risk, and HIV treatment, check out “*Transgender Health and HIV*” in the BETA archive.)

Another painful and telling statistic offered by Keatley: According to data from the San Francisco Department of Public Health, transgender people represented at least 2% of all new AIDS cases between 2004 and 2008, but accounted for 7% of deaths due to AIDS in 2008.

Trans activist Marcela Romero (photo: Ryan Rayburn)

These high rates of HIV infection and severe health disparities, Keatley explained, are driven by such psychosocial factors as transphobia, family rejection, low self-esteem, gender validation through sex, and rampant (and often legal) discrimination in schools, health care systems, housing, and employment. Marcela Romero, co-ordinator of *REDLACTRANS*, a Latin American and Caribbean transgender network, neatly summed up the results of these combined social forces: “I am not a ‘high-risk’ person; I am a member of a community that is *put* at high risk.”

Indeed, Keatley observed, simply being transgender is legal grounds for being denied employment in most U.S. states. Without stable employment, many transgender people turn to sex work for survival, putting themselves at increased risk for HIV infection. “The best intervention you can provide for transgenders regarding HIV is to *employ* them,” urged Keatley.

Other transgender health and rights advocates on the panel joined in calling for an end to discriminatory policies around the world that land trans people in jails and prisons and prevent them from accessing HIV testing, prevention, and treatment (and even basic medical care). Cecelia Chung, a health commissioner for San Francisco, emphasized that transgender rights are human rights, and shared stories of HIV-positive trans women sexually assaulted and left to sicken and die in detention centers. Manisha Dhakal of the *Blue Diamond Society* in Nepal demanded targeted funding for trans-specific HIV programs around the world and input into how the money is used. “We are not consulted for allocation, planning, and designing programs,” she said.

Mauro Cabral, co-director of *Global Action for Trans* Equality*, acknowledged the efforts of his fellow transgender advocates and called for renewed dedication to securing human rights for trans people: “I know we are changing the world together.”

Transgender Health and Legal Resources:

- The *Blue Diamond Society*
- *Center for Excellence for Transgender Health*
- *Global Action for Trans* Equality*
- *GLAAD’s Transgender Resources*
- The Human Rights Campaign’s *Transgender Visibility Guide* and other publications
- *The National Center for Transgender Equality*
- *REDLACTRANS*

Improving Engagement and Retention in Adult Care Settings for Lesbian, Gay, Bisexual, Transgender and Questioning (LGBTQ) Youth Living with HIV

– A Guide for Adult HIV Healthcare Providers

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INTRODUCTION

Every year in the United States, 5,000 young people under 25 years old become infected with HIV, mostly due to unprotected sex or needle sharing.[1] In recent years, advances in anti-retroviral HIV medications (ARVs) have significantly reduced AIDS-related mortality, giving these young people the chance to live long and healthy lives. Whether transitioning out of a pediatric or adolescent care setting into adult care, or moving directly from the point of diagnosis into adult care, young people living with HIV are entering a system that is not set up to meet their needs. Already, young people (15-24 years old) have the lowest utilization of medical office visits of any other age group.[2] In HIV care, this can have a devastating impact on adherence to ARV medication, treatment of opportunistic infections and prevention of transmission to others. Engaging and retaining young people in adult care is critical to their survival and to wider prevention and public health efforts, yet too many continue to get lost in the process.

The specific and often unaddressed needs of HIV positive lesbian, gay, bisexual, transgender and questioning (LGBTQ) youth further complicate this issue. The multitude of psychosocial and structural barriers that they face due to their sexual orientation or gender identity – mental health problems, homelessness, substance use and stigma – within a society that often misunderstands and mistreats them, makes coping and living with an HIV diagnosis particularly complex.

To date, there is scant literature on how to effectively treat LGBTQ youth (13-24 years old) in adult care settings that were infected with HIV via behavioral means. The majority of related research has focused on *transition out* of pediatric care settings for perinatally infected young people and recommendations have mostly targeted pediatric providers. As the population of transitioning and newly diagnosed young people grows, with the highest prevalence within LGBTQ communities, there is an urgent need to bring this topic to the fore among adult care providers. Therefore, the National Alliance of State and Territorial AIDS Directors (NASTAD) developed this issue brief to help health departments explore the unique issues affecting HIV positive LGBTQ youth, particularly those not perinatally infected, and assist adult HIV health providers as they *welcome them into* their care.

The following sections provide a general overview of LGBTQ youth living with HIV, barriers to engagement and a series of simple and applicable recommendations for improving engagement and retention in care for this population.

THE EPIDEMIC

At the end of 2008, there were nearly 40,000 young people, 13-24 years old, living with HIV/AIDS in the United States. Among males, 73 percent of infections were attributed to male-to-male sexual contact and 16 percent to perinatal transmission. Among females, 59 percent of infections were attributed to heterosexual contact and 34 percent to perinatal transmission[1]. Male-to-female transgender youth also have particularly high incidence of HIV infection.[11]

A QUICK OVERVIEW OF LGBTQ* YOUTH

LGBTQ youth have the same developmental challenges as all young people but with the potential added stress of minority sexual orientation and/or gender identity, internal and external homophobia, and limited family and peer support.[3] Institutionalized homophobia within schools, workplaces and health care

* The term "LGBTQ" refers to a large and diverse group of people whose characteristics and needs change from one individual to the next. When reading about the following sub-populations, it is important to remember that these are just a few of the many, and are themselves very broad and general. Sub-groups are not mutually exclusive; youth may fall across many subpopulations or none at all.

settings results in high levels of violence toward LGBTQ youth plus disproportionate rates of substance use, mental health problems, suicidal ideation, school drop-out and sexual risk-taking.[4] Twenty to 40 percent of homeless youth are LGBTQ, often as a direct result of "coming out" to families and being kicked out of the home.[5] Internalized stigma, in addition to living with a condition that is highly stereotyped and misunderstood, only exacerbates these problems. The pervasive discrimination and rejection experienced by so many LGBTQ youth on the basis of their sexual identity and/or HIV status means that in terms of health care and day-to-day life, many are going it alone. Therefore, the ability to reach them at all with healthcare, and then retain them in care, is ever more difficult.

Young Men Who Have Sex with Men (MSM)

Young men who have sex with men (MSM), ages 13-24 years old, are the fastest growing population of people living with HIV in the U.S.[6] and a high percentage do not know they are infected. Alcohol, methamphetamine and other drug use is common among young MSM and can lead to risky sexual behavior. Unfortunately, for young men growing up in an age where antiretroviral (ARV) medications have been readily available, some do not view HIV as dangerous and have become complacent about risky behavior.[7] This concern is heightened with recent advances in pre-exposure prophylaxis (PrEP), Truvada, a promising daily pill to prevent HIV transmission among MSM. Advocates fear that the availability of Truvada for PrEP could lead to a false sense of protection from HIV and increased risk-taking among young MSM.

Young MSM of Color

Rates of HIV infection among young Black men 13-29 years old are higher than among any other races/ethnicities.[8] Young Black gay/bisexual men are hardest hit, representing three-quarters of new infections among all young Black men and more infections than any other racial/ethnic group of MSM. In 2008, 17 percent of young Latino MSM were infected with HIV, with rising rates every year.[8] Many Black and Latino youth are diagnosed late in the course of their infection, putting them at increased risk for opportunistic infections and rapid progression to AIDS.[12] LGBTQ youth of color face special challenges. Not only do they experience stigma and discrimination from society at large because of their sexual orientation, but they may also face rejection by their own racial/ethnic communities, many of which strongly oppose homosexuality. Feeling that they have to choose between their ethnicity and their sexual identities, these youth are less likely to be involved with support organizations and activities targeting LGBTQ youth.[9]

Young Women

Young women who have sex with women (WSW) are often thought of as "safe" from negative health outcomes.[9] However, evidence suggests that many WSW also have sex with men. Over their lifetimes, they have similar rates of sexually transmitted diseases to all women, experience pregnancy at higher rates than heterosexual women and are less likely to use protection during heterosexual intercourse.[9] Therefore, WSW have the same sexual and reproductive health (SRH) needs as women who have sex with men, making adequate SRH services crucial for this population. Studies of pediatric HIV care have found that SRH services are limited in the pediatric setting. Often, providers assume that HIV positive young women do not want to have children or are not having sex. For sexually active young women, the adult care environment may be much healthier and more helpful in providing access to family planning and counseling services.[10]

Transgendered Youth

Male-to-female transgendered youth have particularly high rates of HIV infection and many providers are not prepared to manage the complexities of their situations. Transgendered youth may be taking or interested in taking gender-affirming hormone therapies or other medications in addition to their ARV therapy.[11] They also experience high rates of violence, victimization and suicide ideation.[9] In 2006, the National Institute of Mental Health reported that transgender women were less likely to receive ARVs than all other people living with HIV.[12] It

is less likely that a pediatrician will have any specialization in this area, so finding an adult care provider that is knowledgeable and experienced working with transgendered youth is likely easier and advisable.

WHERE ARE THEY COMING FROM?

Some youth will be transitioning out of pediatric health settings, while others will go straight into adult care after diagnosis. NASTAD recognizes the importance of understanding these contexts, in addition to how mode of transmission can impact engagement and retention in adult care.

Pediatric/Adolescent Care

Young people that contracted HIV at birth or early in adolescence are likely to have received care in pediatric and/or adolescent health facilities for many, if not all of their adolescent years. Clinically speaking, perinatally infected youth are more likely to be in advanced stages of HIV, with a history of opportunistic infections, co-morbidities, developmental delays and more resistant mutations of the virus resulting in complex medical regimes.[3] Their psychosocial needs are largely the same as those of their behaviorally infected peers. In pediatric/adolescent care, medical and psychosocial needs are often addressed together, through a multi-disciplinary, "1-stop shop" model. Coordinated services such as these are less likely to be available in adult care settings.

Youth's strong attachment to their adolescent care team, particularly among those who have not disclosed their HIV diagnosis to anyone outside their providers, makes leaving that team particularly challenging. Mutual feelings of attachment, coupled with distrust of the adult care system, mean many pediatric/adolescent providers are equally resistant to let go of their patients.[4,5,6]

Point of Diagnosis

Depending on age, age at diagnosis, readiness and/or clinical protocol, many young people will go directly to adult care without ever entering pediatric or adolescent HIV care settings. Some newly diagnosed youth enter a period of denial after receiving a positive test result, meaning they do not always enter care right away. Equally, a recent diagnosis may mean that youth are still learning to cope, considering suicide and unable to take responsibility for their care. They may experience more challenges to treatment adherence, have denial and fear of HIV, have misinformation about HIV and about their personal risk. They will likely have more distrust of the medical establishment, fear, disbelief in the effectiveness of treatment, low self-esteem, depression and anxiety, and an unstructured and chaotic lifestyle without family and social supports.[7]

These youth are likely experiencing illness for the first time in their lives, necessitating increased assistance with how to navigate the health care system, treatment adherence and health insurance benefits. If new to the health system overall, young people may bring previously unaddressed issues of substance use, anxiety and depression, intimate partner violence and others that require immediate attention.

KEY STRATEGIES FOR ENGAGEMENT IN CARE

This section will provide simple and applicable solutions for improving and increasing engagement in care for HIV positive LGBTQ youth. As with any young person, the overarching goals for treating LGBTQ youth are to promote healthy development, physical health, and social and emotional well-being.[8] For HIV positive youth, those goals also include increasing self-care behaviors, medical adherence and health-related interactions; reducing transmission and high-risk behaviors; and enhancing quality of life.[13]

Avoid Assumptions

One of the most important components of working with LGBTQ youth is to never make assumptions, particularly when it comes to sexual identity, gender and behavior. Assumptions can lead to missed information during patient visits or worse, a breakdown of trust.

Asking the Right Questions Can Make a Difference	
Young people may identify their sexuality differently from the way they behave.	**Ask whether the patient has had sex with men or women or both, regardless of how he/she identifies.**
Sexual behavior and identity can change over time.	**Ask about previous sexual behavior or sexual desires at every visit.**
Being in a committed relationship does not always equal monogamy.	**Ask questions about concurrent sexual partners.**
Youth may only identify sex as penile-vaginal intercourse.	**Ask about whether he/she has had vaginal, anal or oral sex in the past.**
Gender identity is distinct from sexual orientation.	**Don't assume transgender implies gay.**
Your patient is also an expert.	**If you need help with all of these terms, ask the patient to help define them!**

Adapted from Fenway Guide to LGBT Health Module 2

Create a Welcoming Environment

"One of the most important things that an adult provider needs to recognize is that first impressions are everything. If youth don't feel welcome or they are made to feel inferior or not intelligent -- especially if they are not cognitively ready to navigate the situation -- chances are they are not coming back and they will be lost to care" (Male, 29, Ohio).

"In our adolescent clinic, the walls are covered in graffiti and there are resources and flyers for youth. It's open on Saturdays. The adult clinic is not youth-friendly. The problem is that if they [youth] don't like it, they won't go" (Male, 20, Boston).

Pediatric and adolescent health settings are often decorated with culturally and age-appropriate artwork, equipped with relevant resources and brochures, and staffed by people that are enthusiastic about working with youth. An adult care environment that seems sterile and filled with people with whom youth cannot identify (e.g., older, sickly, etc.) could keep a young person from returning for care.

Creating a youth and LGBTQ friendly environment is a crucial component of services for HIV positive LGBTQ youth.

Creating a Youth-friendly Environment*	Creating a LGBTQ-friendly Environment**
Hold **flexible clinic hours** on weekends and in the evenings.	Provide comprehensive **training** for all clinic staff in the care and rights of LGBTQ youth. Make sure to include "frontline" staff; those that youth will interact with when they first walk in the door.
Cluster medical and mental health appointments together, and schedule them alongside other peer support and case management activities so youth have more of a **"1-stop shop".**	Make sure someone is there to greet young people when they walk into the clinic so they feel **welcome**.
Provide **travel** vouchers for public transportation.	Have posters and flyers with same-sex couples and transgendered youth.
If possible, create a **separate waiting area** for youth in which they can congregate, check email, etc. Provide **childcare** for youth with small children.	Provide information about safe sex, HIV prevention, and/or pregnancy prevention that is **appropriate** for LGBTQ youth (e.g., resources that only talk about heterosexual couples may not be received well).
Integrate intensive **case management** and relevant psychosocial support services.	Provide appropriate resources and referrals for **LGBTQ-friendly services** such as mental health, substance use and peer support.
Actively **involve** young people in program design and delivery.	**Involve** LGBTQ youth in the planning, delivery and evaluation of your program.
Expand **social media** use for engagement and retention (e.g., mobile phones and Facebook for appointment and medication reminders, and accessing results. Give youth beepers when they arrive for care so that they can leave the waiting room and be called back when they are ready to be seen.)	Discuss racism, sexism, homophobia and other forms of cultural oppression in your program. Get young people to generate ways to solve, limit or minimize the problems caused by cultural oppression.
Provide information and materials that are appropriate for young people.	**Refer** patients to providers that are enthusiastic about working with LGBTQ youth.

* *Adapted from Young Adult Program, St. Lukes Roosevelt Hospital, New York City.*
** *Adapted from Health Initiatives for Youth, San Francisco, California.*

Address Institutional Stigma

Few population-based studies have documented health disparities among LGBTQ people, and even fewer on LGBTQ youth. However, widespread anecdotal data, from patients as well as practitioners, provide evidence that failures in the system remain. LGBTQ patients often face difficulties in accessing quality health services due to stigma, both real and perceived, within the medical community. Lack of education and training for health professionals surrounding the specific needs of LGBTQ youth, and communication shortfalls during clinical visits,[3] can have an enormous impact on a patient's health-seeking behavior and adherence to health recommendations. This fact cannot be overlooked when it comes to LGBTQ youth who often experience high levels of distrust of the health care system.

Young people return to environments where they know people care for them[2] so be empathetic, non-judgmental and kind. Remember that most HIV positive and LGBTQ youth have experienced a tremendous amount of trauma in their lives and have faced incredible adversity. Shifting your model of care from a "deficit" approach to an "asset," or resiliency model, will help them focus on a continuum of life rather than just a continuum of care.[2]

Building a positive relationship with your patients*
Spend **extra time** with new patients, helping them understand the significance of learning and understanding their lab results, adherence and building relationships with providers.
Get to know the patient as a **person** (e.g., partners, jobs, interests). Ask open-ended questions, like "What do you like to do for fun?" Help validate that they are "normal" youth.
Assist youth with their autonomy and self-acceptance, concerning both their sexual orientation/gender identity and their HIV status.
Encourage young people to keep a **list of questions** for you, perhaps in their phones, so that they feel prepared and confident when they attend appointments.
Create **open and honest** dialogue, particularly around sensitive issues. Remind them that what they say is confidential and that they can trust you.
Ask **non-judgmental questions** about sex, sexuality and sexual identity. Ask questions in a way that does not assume sexuality. For instance, instead of "Do you have a boyfriend/girlfriend?" ask, "Are you in a relationship?"
Respect and address **confidentiality** proactively – do not assume whom the young person has told about his/her sexual identity or HIV status, including other providers.
Be prepared to make appropriate **referrals and recommendations**, particularly for case management, mental health, housing, substance use and peer support.
Let youth use **their own terminology** for their sexual identity even if it does not match their behavior. For instance, some MSM do not identify as gay. Rather than ask, "Are you gay?" ask "Have you ever been sexually involved with men, women or both?"

* *Adapted from Fenway Guide to LGBT Health Modules 2 & 4. See these modules for comprehensive training on patient interviews with LGBTQ youth.*

Recognize the Individual; Treat the Whole Person

> *"Often providers expect youth to be fully able to engage in care the same way an adult will; that is not the reality. Especially if they have never dealt with care settings or have always had it dealt with for them. There are small steps that any setting can take to engage youth in a way that it is going to be affirming, accepting and meeting them where they are" (Male, 29, Ohio).*

There is no prescribed age for transition to adult health care, though the majority of U.S. clinicians try to transition HIV positive youth into adult care by the age of 24.[17] That being said, chronological age is very different from developmental age, and the latter, in addition to patient readiness, is crucial to determining healthy engagement in care for HIV positive youth.[14] Assessing the patient from an ecological perspective, taking note of all of the biopsychosocial determinants that influence his/her health, in addition to making appropriate referrals for wrap-around services, is essential. With recent evidence that ARVs can prevent HIV transmission among sero-discordant couples,[15] support and education surrounding adherence become ever more crucial. Where possible, involve a social worker and/or case manager who can assess and address pressing issues. If a young person is transitioning from a pediatric/adolescent care setting, communicate with the provider team about how best to coordinate these services.

Addressing important psychosocial support needs
Adherence: Recognize that adherence to their ARV regimens is especially hard for young people living with HIV, particularly if they are struggling with many other aspects of their lives. Ensure that adherence support, through peer and professional counseling, is provided for all young people taking medications.
Substance use: Some youth need harm reduction education, motivational interviewing and/or introduction to rehabilitation and recovery therapy.
Longer-term housing: Transitional living programs for homeless youth offer an active alternative to shelters and can be designed to meet the specific needs of this sub-population.
Mental health: Understand that depression, anxiety and suicide ideation are both predictors and consequences of an HIV diagnosis. Screen for these issues and refer appropriately.
Disclosure: Recognize that disclosure of HIV status to others is one of the biggest concerns for HIV positive youth. Provide information and counseling surrounding healthy and safe disclosure to others.
Partner violence: Many LGBTQ youth living with HIV face high rates of intimate partner violence, particularly after disclosing HIV status. Programs should incorporate counseling, support and education surrounding domestic violence.
Peer support: Peer support can be offered through regular support groups, one-to-one mentorship, youth conferences, and social activities where education is provided in a fun setting. The role of older peers who have successfully transitioned and are engaged in adult care, who can serve as mentors, cannot be overstated.
Structural support: Link youth to services and programs that focus on money management, credit, decision-making skills, job training and educational opportunities.

Solve Access Issues

Health care access is a major issue for HIV positive LGBTQ youth due to lack of insurance, homelessness and unemployment. In rural settings, patients must travel a substantial distance for HIV, mental health and substance use care.[2] Many young people fear disclosure by insurance companies to parents or guardians so they access care in community-based settings that do not require health insurance.[9] LGBTQ youth may not know where to go for LGBTQ and youth friendly care, and one negative experience could persuade them to disengage completely.

A recent study by the Health Resources and Services Administration (HRSA) found that newly diagnosed, HIV positive young Black MSM are more likely to go to their first doctor's appointment if the person who diagnoses them picks up the phone and schedules that appointment.[16] This simple gesture can be lifesaving.

Providing Access to Comprehensive Services
Provide **case management** services to support youth with transportation, health insurance and benefits.
Offer travel **vouchers** or bus fare.
Link youth to **peer support groups** that can help keep them engaged.
Have a **list of providers** within the region ready at each point of diagnosis to ensure successful referrals into care.

Highlight Sexual and Reproductive Health (SRH)

Comprehensive, LGBTQ and youth-friendly SRH services are essential for this population. Young people may engage in sexual risk-taking as a coping mechanism to deal with a recent diagnosis, feelings of hopelessness or preoccupation with illness. They may also engage in unsafe sex as a means of gaining peer acceptance and coping with experiences of stigma.[17] Sexual curiosity and risk-taking are inevitable components of adolescent development. Like their uninfected peers, young people living with HIV have the right to seek sexual fulfillment and they should be equipped with the knowledge and skills to protect themselves and their partners.

Providing sexual and reproductive health services
Support young people with information and education surrounding positive sexual health and prevention, self-esteem, self-efficacy and the ability to manage high-risk situations.
Provide social support services and counseling surrounding **family planning** and parenthood.
Link pregnant youth to appropriate **antenatal care** and education and counseling on how to reduce the risk of mother-to-child transmission during pregnancy, delivery and breastfeeding.
Ask youth about their **fertility intentions** and desires. Recognize that expectations for sex, intimacy, loving relationships, children and family are no less evident in HIV positive young people or in those that are LGBTQ.
Provide appropriate support for youth involved in **survival sex work** (providing sex for money or resources), particularly if they are homeless.
Provide **assertiveness training**, particularly for those youth still struggling with "coming out." This should include training on condom negotiation and communicating about safe sex options.

Strengthen Youth Voice…and Listen

The meaningful involvement of young people living with HIV in the planning and delivery of their care and support is a critical and often under-addressed component of youth engagement in adult care settings.[18] Putting youth at the center of their care will not only ensure that their individual needs are met, but that the system as a whole becomes more welcoming and sustainable for young people over time.

Involving youth
Create a **mechanism for young people** to provide feedback to providers about the quality of care they are receiving. Examples include a youth advisory board, anonymous suggestion boxes and simply asking them during visits.
Teach **decision-making skills** so youth are able to make informed decisions around high-risk behaviors as well as important decisions about their healthcare.
Create **safe spaces** for young people to meet and network with one another within the clinic setting. Knowing they are not alone will strengthen their voice and their incentive to stay engaged in care.
Provide paid or volunteer **opportunities for young people** to work in the clinic, particularly as peer educators and counselors.
Introduce youth to peer education trainings, advisory boards and other outreach opportunities that will strengthen their ability to **advocate for themselves.**

CONCLUSION

LGBTQ youth living with HIV in the U.S. remain a hidden population. Stigma and misunderstanding at the individual, community and institutional levels, coupled with a health care system that is not prepared to receive them, pave the way for a disease burden that is impossible to manage. Failing to successfully engage and retain these youth in adult care not only jeopardizes their health and wellbeing; it threatens the success of HIV prevention efforts to date, which could cost valuable lives and resources. It is timely and urgent that we shift our focus to retaining HIV positive LGBTQ youth in adult care, and begin an honest dialogue with young people and one another about how we are going to do it.

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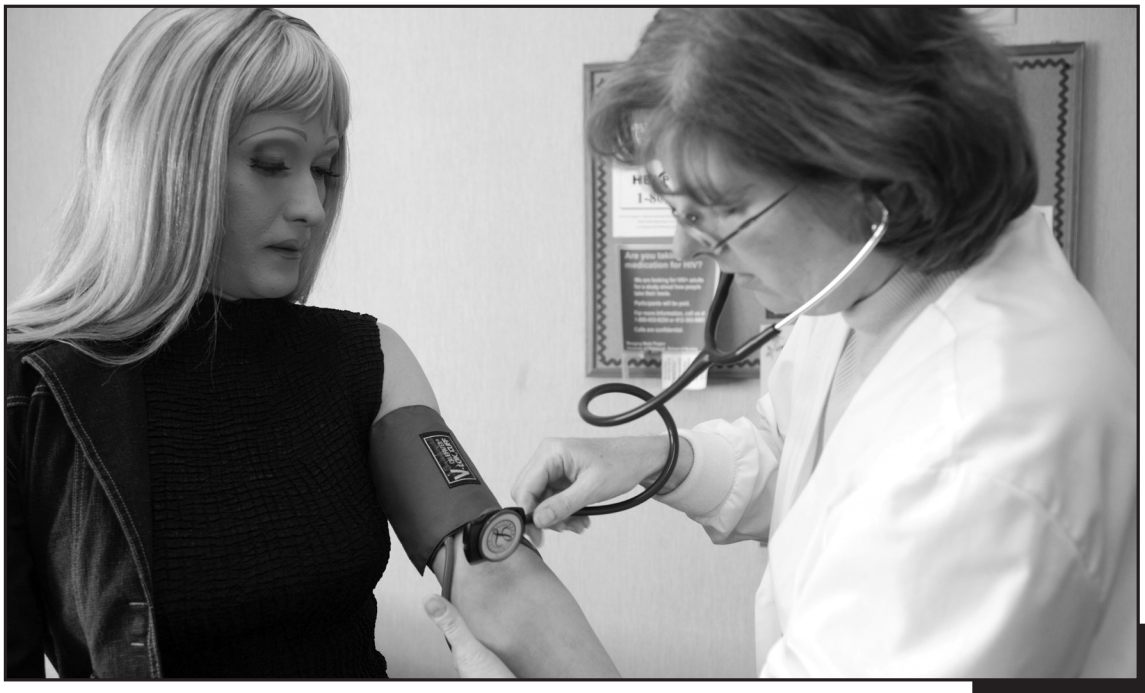

Health Issues

Systemic Barriers

Cultural Competency

Clinical Competency

TRANSGENDER HEALTH

The term *transgender* describes people whose gender identities differ from their anatomic sex. Transpeople may seek to alter their bodies in a variety of ways, or decide against any medical intervention. Transmen and transwomen (see box, "Terminology 101") may express their gender identity through a myriad of presentations and behaviors, hoping to "pass" and be accepted in their preferred gender.[1,2] Transpeople come from every walk of life, every sexual orientation, and every region of the country. Some may identify not as transgender but simply as male or female, or they may choose not to identify with any gender labels at all. There are many cultures and subcultures represented within transgender communities, each with rich and varied expressions of gender identity.

Transpeople as a group experience health disparities including difficulty accessing care and a lack of medical providers able—or willing—to address their needs. Compounding these challenges, some transgender subgroups, such as recent immigrants, youth, the homeless, and those with unstable or no employment, often find themselves in transient circumstances, making engagement, enrollment, and retention in health care, and social services all the more difficult.[3]

The size of the transgender population is largely unknown, primarily because surveillance data often excludes or miscounts transpeople (e.g. transwomen being placed in the category of men who have sex with men [MSM]). Lack of national data on the transgender population affects funding for prevention, outreach, testing, and health care focusing on transpeople. It also hinders public health professionals from better understanding and addressing transgender needs. Additionally, transgender health is traditionally taught under the umbrella of psychiatry and psychology and is not a standard part of the core primary health curriculum in most medical schools.[5]

DID YOU KNOW?

- Estimated HIV rates are higher among transwomen than any other subpopulation;[4] Ryan White grantees have an important role in addressing this and treating the trans community.
- Steps like posting trans-friendly materials in provider waiting rooms and having single-occupancy bathrooms go a long way in making transpeople feel welcomed and comfortable in your clinic space.

U.S. Department of Health and Human Services
Health Resources and Services Administration

DIRECTOR'S LETTER

Transgender women are more disproportionately affected by HIV disease than any other subpopulation. According to a U.S. Centers for Disease Control and Prevention meta-analysis, more than one-half of HIV-positive transwomen were unaware of their status, underscoring the need to increase attention, testing, and treatment of this population.

Though HIV rates are much lower among transmen, they have unique health care needs and may still be at risk for infection. As such, we must continue to do more to become clinically and culturally competent in addressing transgender health needs.

There are many subcultures that exist within the transgender population but despite its diversity, one thing is clear: Ryan White HIV/AIDS Program providers have a big role to play in increasing access to and efficacy of HIV primary care to this population. The Ryan White HIV/AIDS Program has always prided itself—in fact it built itself—on patient-centered, comprehensive care to those most in need and that is why we're devoting this issue to *HRSA CAREAction*, so together we can do more for our trans patients and curtail the epidemic within this community.

Deborah Parham Hopson
HRSA Associate Administrator for HIV/AIDS

HRSA CARE Action

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Photographs
Cover: A patient and provider at the Ursuline Sisters HIV/AIDS ministry in Youngstown, Ohio. Photograph by: Ben Fraser

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HIV/AIDS

Prevalence

The percentage of U.S. transpeople who are HIV positive is unknown, but estimates place HIV prevalence among this population as the highest in the Nation.[4] The California Department of Health Services found that self-identified transgender clients—specifically, transwomen—had the highest proportion of HIV diagnoses, greater than high-risk populations such as MSM and partners of people living with HIV/AIDS.[4]

Furthermore, findings suggest that a significant proportion of HIV-positive transwomen are unaware of their status. Data-based assessments point to high HIV risk among transpeople, self-perception of risk is often low,[2] signaling a need for increased prevention education and awareness. A U.S. Centers for Disease Control and Prevention (CDC) meta-analysis of 29 studies on transwomen found the average HIV prevalence was 28 percent when results were lab confirmed, but that prevalence was 12 percent by self-report.[4] In addition, the CDC analysis found African-American transwomen to have the highest prevalence regardless of test assessment with 56 percent testing HIV positive, and 31 percent self-reporting a positive status.[4]

In contrast, HIV prevalence among transmen is low. A study in the *American Journal of Public Health* reported 2-percent prevalence of HIV infection in this population. Other studies have estimated prevalence ranging from less than 1 percent to 3 percent. More studies are necessary to better understand this population and its specific risks.[6]

Factors Contributing to HIV Risk and Health Disparities

Stigma

Transpeople face an enormous amount of stigma, which often leads to lower self-esteem; depression; and increased likelihood of survival sex work, substance abuse, and risk-taking behaviors.[2] Social marginalization can result in denial of employment, housing, and even educational opportunities.[2] Stigma can manifest in multiple ways; it can appear as overt or covert discriminatory practices against members of a stigmatized group, and it is often internalized among members of that group. It arises in part from a lack of the public's understanding of a population and its needs.[7]

Many transpeople face other sources of stigma, including HIV status, sexual orientation, sex work, and race/ethnicity, further compounding the challenges they face and the need for appropriate messaging and education. In addition, many transpeople have had negative past experiences with the health care system due to the insensitivity, ignorance, or discomfort of medical providers, creating further barriers to engagement and retention in care.[8] Some do not

want to access HIV services at clinics frequented by other transpeople because they fear losing anonymity. Those fears may be alleviated if the clinic isn't known as an HIV clinic but, instead, as a primary health care clinic offering hormone therapy.[3]

Sex Work and Survival Sex

In a Los Angeles study, more than one-half of transwomen reported a history of sex work. For some transwomen, sex work provides affirmation of their gender identity, and it may help fund sexual reassignment, silicone injection, or cosmetic surgery. Transpeople, particularly transwomen, experience high rates of housing discrimination as well as employment discrimination, which often leads to homelessness—both cited as contributing factors to survival sex.[4,6,9,10] While many transpeople engage in sex work for a variety of reasons, it places this population at increased risk for HIV and is one contributing factor to high rates of incarceration.[11,12]

Unprotected Sex

Risk factors such as multiple sexual partners and irregular condom use are common in the transgender community.[2] Examples of sexual risk factors include:

- Eighty-five percent of transwomen in a San Francisco Department of Public Health project reported receptive anal intercourse without a condom on a lifetime basis.[8,13]
- Furthermore, transwomen who perform commercial sex work have reported that they are often paid more for services if they do not wear a condom, increasing their risk for HIV.[8,14]
- Although HIV prevalence among transmen is much less than among transwomen, an important study on transmen who have sex with nontrans men (also commonly referred to as gay transmen) consistently reported not using condoms during receptive anal or vaginal sex.[15]

High rates of HIV among transwomen place their sexual partners at increased risk for acquiring HIV. Conversely, trans MSM have reportedly low incidence, but their sexual partners (nontrans MSM) have high rates of HIV, placing trans MSM at increased risk.[15] Little HIV prevention messaging targets transgender populations or their partners. Improved prevention messaging that takes partners into account and relates to the everyday reality of transmen and transwomen is required to adequately increase awareness and reduce rates of HIV transmission.[15]

Silicone Use

Many transwomen inject silicone as a fast, cheap alternative to hormone therapy or cosmetic surgery. It assists in giving them a more feminine body shape (curves) which helps them "pass" in public. (Passing also provides a measure of safety from discrimination and hate crimes.[16]) Silicone use also preserves male sexual drive, which is usually suppressed by hormonal therapy, offers quicker results than hormone therapy, and is cheaper than cosmetic surgery. Silicone injection, however, is not legal and carries numerous health risks. Medical silicone is hard to obtain, so other fluids are often injected as substitutes including lubricants, sealants, grease oil, and other toxic materials not meant for bodily injection.

Transwomen may attend "pump parties" where they take turns injecting silicone, often in unsanitary conditions. The sharing of injection needles carries the risk for HIV and hepatitis. Silicone often hardens and migrates over time, leading to systemic illness (i.e., medical complications of tissues and organs), disfigurement, or even death.[17] Some transwomen may be reluctant to give up silicone use, and providers should therefore consider harm reduction strategies to educate them about needle sharing.[18]

As Earline Budd, founder of Transgender Health Empowerment cautions, "At the end of the day, all the counseling in the world just does not seem to heal the wounded heart of a transgender woman who says she wants breasts overnight." Budd adds, "This is where we hope word of mouth can help, that if we educate our clients about the risks of silicone that they'll let others know, too."

To counter silicone use, Madeleine Deutsch, physician at the Los Angeles Gay & Lesbian Center's Transgender Health Program, displays a picture of a patient who is deformed because of silicone. "The woman's chest wall is a rock-hard mass," says Deutsch. "The patient gave me permission to use her picture to educate others. The sad thing is, she'll likely die from this."

Violence and Victimization

Distrust of police and the criminal justice system, along with fears of further victimization, often result in underreporting of violence against transpeople. Violence against this group, particularly against transwomen of color, is believed to be rampant, however. Several urban needs assessments and behavioral risk studies, along with data from *Remembering Our Dead* (an online memorial for deceased transpeople), support findings of victimization, domestic violence, and hate crimes.[19]

Sexual violence against transwomen is extraordinarily high. In San Francisco, the health department found that 59 percent of transwomen have been raped.[8,13] Another study of 402 transpersons revealed that more than 50 percent reported experiencing some form of harassment (e.g., bullying) in their lives and 25 percent reported experiencing a violent incident.[20,21] Even in shelters, transpersons experience discrimination as a result of gender segregation policies—which can place transpersons at risk for shelter violence, as they may be housed with persons uncomfortable by their presence and subsequently assault them.[12]

Harassment in school and employer discrimination prevent many transpersons from completing their education, keeping jobs, or feeling safe and accepted—conditions associated with high risk behaviors that can cause HIV infection.[22] Some studies have found that approximately 1 in 4 transwomen have not received a high school diploma. Among transgender Latinas, this number may be as high as 1 in 2.[21]

A needs assessment for the Boston Health Care for the Homeless Program found high rates of verbal and emotional harassment among their transwomen patients (both at the clinic and on their way to the clinic). In response, the program instituted evening hours so these patients could feel safe and welcomed. As Pam Klein, a nurse at the program, explains, "All of the issues of a vulnerable, marginalized group are present among this population. The issues themselves aren't necessarily different, but they are worse."

Incarceration

High rates of sex work and drug use can lead to incarceration and overrepresentation of transwomen in prisons and jails. An estimated 37 to 65 percent of transwomen have been incarcerated at some point in their lives.[12] Incarceration can be particularly stressful for transpeople because they are often housed according to whether they have undergone genital surgery; are often without hormone therapy; and are at increased risk for discrimination, violence, and unprotected sex.[23]

DEPRESSION

Rates of depression are higher among transpeople than among the general public. Suicidal ideation among transwomen is in epidemic proportion. The CDC meta-analysis found that across studies, an average of 54 percent of transwomen reported suicidal thoughts and an average of 31 percent reported lifetime suicide attempts.[4] Like transwomen, many transmen suffer from low-self esteem, high rates of depression, suicidality, substance use, and risk taking.[24]

Transpersons may also suffer social isolation that ranges from discomfort in public settings to fear of partner rejection to limited family and friend support.[25,26,27,28] Transpeople who identify as gay, lesbian, or bisexual sometimes feel that they are not truly welcomed within those communities, further contributing to social disconnectedness.[28] Several interviewees stated that the sentiment "two is a crowd" is common within the transgender community—that is, the fear of being outed in public and the concomitant threat to personal safety means transpeople can even feel concerned about being seen with their peers in public. Feelings of isolation are compounded for transpersons who don't "pass."[29]

SYSTEMIC BARRIERS

Insurance

Even transpeople with health insurance face significant barriers because hormone therapy and sex reassignment surgery are commonly excluded by U.S. health insurers. In fact, transpeople are the only population required to have some sort of psychiatric evaluation before cosmetic surgery, a requirement often seen as stigmatizing.[5] A formal diagnosis of gender identity disorder, however, is sometimes a "necessary evil" to ensure that patients have access to appropriate and necessary mental health services[30] and health insurance coverage.[31]

Insurance companies may deem necessary procedures (e.g., a transman needing a hysterectomy) as sexual reassignment surgery and may deny claims.[16] When challenges arise from billing requirements and gender identification, providers should explain the situation to the patient and discuss options for how to proceed.[18] This may include physicians and support staff members interacting with insurance claims processors on behalf of their transpatients. Providers may also use nonspecific diagnostic and procedural codes to work around the issue.[32]

Substance Abuse Treatment

Substance abuse treatment (both inpatient and outpatient rehab) can present barriers to transpeople including provider insensitivity, strict gender segregation, and requirements to refrain from hormone use.[12,19,33] Providers should refer patients to trans-friendly treatment facilities where hormone use is not considered substance use.

Legal Issues

Identification documents (ex. birth certificates and drivers licenses) often do not match the gender or name of the transperson, thus causing barriers to employment or to qualify for social services.[12] For legal purposes, only sex (either assigned at surgery, or if changed through surgery) is used on most documents. Even if intersex persons (those with chromosomal abnormalities, mixed sex characteristics and, rarely, ambiguous genitalia) are assigned a sex at birth.[7] As of June 10, 2010, however, sexual reassignment surgery is no longer a prerequisite for passport issuance in a transperson's preferred gender; now applicants need only present a certificate from their physician indicating treatment for gender transition (but not surgery).[34] Still, name and sex changes continue to pose barriers to appropriate identification, which itself becomes a barrier when accessing services.

Electronic Medical Records

Electronic medical records (EMRs) sometimes do not have transgender-specific options. Such systems make it more difficult for transpeople to change their sex designation. Some EMR systems may permit a change but retain a record of the change that can be seen without the need for the physician or patient to provide permission. Such systems leave transpatients vulnerable to exposure and discrimination.[32] Carole Hohl, director of HIV services at the Boston Health Care for the Homeless Program, explains, "We include preferred name in a chart alongside legal name, which is a trigger to other providers so they know what name to call the patient and helps avoid creating billing issues." Clinics are encouraged to adopt flexible EMR systems or develop workarounds like the one Hohl describes.

CULTURAL COMPETENCY

According to the *Transgender HIV/AIDS Health Services Best Practices Guidelines*, providers should be able to talk about a range of health care and social issues that affect transpersons, such as safe and unsafe ways to modify their bodies and appearances, sexual risk behaviors, mental health and substance use issues, intimate partner violence, housing,

TERMINOLOGY 101

Gender
A system of classification used to describe characteristics and behaviors ascribed to bodies. Sex and gender are believed to be independent of each other.

Gender expression
The way in which a person communicates their gender to others.

Gender identity
A person's sense of their own gender

Gender identity disorder
Diagnosis used by psychologists to describe persons who suffer from severe gender dysphoria (discontent with biological sex and/or gender assigned at birth).

Intersex (formerly called hermaphrodites)
Persons born with chromosomal or physiological anomalies and/or ambiguous genitalia.

Outing
Revealing a transgender person's status without his or her permission.

Passing
Refers to trans persons who are successful at presenting in public in their chosen gender.

Sex
Refers to anatomy and biology.

Transgender
People whose gender identities are different than their anatomic sex.

Transitioning
The process of moving from one sex or gender to another.

Transman (also known as female-to-male, or FTM)
A man classified as female at birth but who identifies as a man and expresses a male gender identity.

Transsexual
A person who has undergone steps (e.g., hormones, surgery) to attain the physical characteristics concurrent with their gender identity.

Transwoman (also known as male-to-female, or MTF)
A woman classified as male at birth but who identifies as a woman and expresses a female gender identity.

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immigration issues (if applicable), hormone therapy, and surgery.[18] Providers are encouraged to create patient satisfaction surveys that address patient comfort with clinic providers.[18] Providers have the most success when their approaches take race and ethnicity into account and incorporate involvement from the community.[35]

Training and Addressing Misconceptions

Trainings should be implemented for all provider staff, including receptionists, and provide information on local transgender-specific resources, sexual orientation and gender identity issues, transgender culture and its diversity, sexual and other forms of harassment as well as domestic violence and anti-discrimination laws.[18] In addition, it should provide communication skills training to ensure use of culturally appropriate language.[18]

Training should address misinformation. As Deutsch explains, "There are a lot of misconceptions about transpeople. There's a sense they all fit the same demographic profile [and that they] are transitioning to realize their sexual identity, but sexual identity and gender identity are completely different."

Providers shouldn't assume all transpersons are seeking or have had gender reassignment surgery; there is no one way—or right way—to gender transition.[36] Transitioning can be a difficult time, and peer mentors who are open about their transgender status can be important resources and sources of support, especially for young transpeople.[22]

To demonstrate that a clinic is transgender friendly, it is important to have materials in the waiting room that are specific to this population. Clinics should also post antidiscrimination policies and provide written hiring policies indicating the organization's desire to employ qualified, diverse candidates.[18]

Flexibility

When possible, clinics should consider flexible hours. Flexible hours are particularly helpful for transpersons engaged in sex work.[3] Others may simply feel more comfortable attending clinic during off-peak hours. Additionally, availability of single-occupancy bathrooms rather than gender-specific bathrooms will help ensure that patients are neither outed nor uncomfortable, and it relieves staff from having to choose a bathroom to which to direct a transperson.

Referrals

Providers should also make contact with trans-serving community organizations; have comprehensive referral lists for trans-friendly resources and health services; be actively involved in making referrals and following up; and refer transpersons to a specific contact person so they know whom to ask for and feel more comfortable inquiring about services. Providers should also discuss with patients whether it is important to disclose their gender to the new agency so the transperson's needs can be adequately addressed.[18]

Use of Pronouns

Clinics should respect what gender a client says he or she is. If providers are in doubt, they should ask the patient politely and discreetly what his or her preference is. Use of gender-neutral language ensures inclusion of all transpersons and avoids inadvertently "outing" someone in public. It's also important to understand that

> Patients may wish to be labeled male or female according to their gender identity and expression, their legal status, or according to the way they are registered with their insurance carrier. They may wish to be referred to as female in one situation (e.g., in their record with the physician's office and in personal interactions with the physician and staff), but male in other situations (e.g., on forms related to their insurance coverage, lab work, etc.). This application of terminology could change at any time as individuals come to understand or evaluate their gender.[32]

CLINICAL COMPETENCY

"Regardless of their socioeconomic status, all transgender people are medically underserved."[37]

As Jessica Xavier, project officer at HAB, explains, "When seeing a new provider for the first time, the very act of disrobing can make a transgender patient feel unsafe. Many patients have had negative experiences with health providers and can find the notion of a physical exam terrifying." It is recommended that providers delay sensitive exams, if possible, until patients become more comfortable.[38]

Providers should ask only questions directly pertinent to the patient's health, and not out of curiosity.[39] If sensitive questions are required (e.g., during an HIV or STD assessment), the following approach is recommended by HRSA's AIDS Education and Training Center:

> I will be discussing some sensitive topics with you today. I will be asking you questions about your sexual behavior and will ask you what body parts you use for sexual activity. I am asking you these questions in order to help you best assess your HIV and STD risks so that we can keep you and your partners healthy. I do not want to assume anything, and most of all I want you to feel comfortable speaking with me today. If you prefer I use other language or words to describe a body part or activity, just let me know. Please feel free to ask me questions any time.[7]

Physical exams should be conducted on the basis of the organs present rather than the perceived gender of the patient. Measures such as smoking cessation, exercise, and family history, remain important to include in general health maintenance discussions.[18] JoAnne Keatley, director of the Center of Excellence for Transgender Health explains that a lot of primary care doctors already have the skills required to address transgender primary care needs and thus, shouldn't be deterred from treating trans patients.

Remember that the presence of a transgender patient is not a training opportunity for other providers. "I really advocate that physicians be willing to learn from their patients but not make the patients teach them," says Keatley. "Putting trans patients in the role of the educator is unfair. They don't have the medical background and, in fact, may have low health literacy."

Mitigate patient worries around the confidentiality of client-level data and assure patients that any patient-specific information disclosed among medical staff is restricted to appropriately addressing their health needs. Providers should also create a nonjudgmental environment where patients feel comfortable discussing any risk-taking behaviors.[18]

Hormones

Hormone therapy plays an important role in the anatomical and psychological gender transition for transpeople and may be necessary for successful living in the person's preferred gender (Figure 1).[18] In addition, hormones are considered to improve quality of life and decrease psychiatric issues, because patients feel like members of their preferred gender.[31] "Transwomen are typically given estrogen and testosterone blockers," says Deutsch. "Progesterone may be tried if they're having mood issues or their libido is too low, but this certainly isn't used for everyone. For transmen, we just give testosterone."

Administration of hormones is not to be taken lightly and it is recommended that patients who take them be at least 18 years old (unless with parental consent); demonstrate knowledge about what hormones can and cannot do; and be able to document real-life experience of either at least 3 months living in their preferred gender, or, receipt of psychotherapy and have a mental health professional's recommendation.[31] "I use the informed consent model. I do a half-hour intake with the patient, make assessment of patient ability to make informed decision, similar to how you would assess someone who comes in for plastic surgery. They need to demonstrate capacity to understand risks and provide necessary self-care as well as comply with a regimen," explains Deutsch. Says Hohl, "We try to use administration of hormones as a chance to do education. . . . If someone's labs come back and it's clear they're using other hormones, then we'll do individualized education with them and we'll adjust how much hormone we're giving."

Although many changes due to hormone therapy are reversible, some are not. To maintain these changes, hormone therapy must continue throughout one's life. Thus initiation of hormonal therapy is a serious commitment and it should be administered by a physician after adequate assessment.[31] Hormone use should also precede any sexual reassignment surgery interventions.[31]

Adolescents may be eligible for puberty-delaying luteinizing-hormone releasing hormone (LHRH) agonists (i.e., testosterone blockers, estrogen blockers) as soon as puberty has set in, although parents need to make informed decisions and provide consent. Delaying puberty affords more time to explore gender identity and other developmental issues, and the therapies may make passing easier which can aid in this exploration. Another factor is that this intervention is fully reversible.

Whenever possible and medically appropriate, providers should make onsite hormone therapy available to transgender clients. This single component of care for trans patients is an important and reliable draw that can counteract other barriers to HIV care. Offering onsite hormone therapy allows providers to better monitor HIV-positive patients' antiretroviral adherence, reduce risk of unsafe street drugs, and link patients to support services. Although there are some risks associated with hormonal therapy (outlined in Figure 1) according to Deutsch, today's newer therapies carry substantially less risk than they used to. She encourages HIV care providers not to be dissuaded from considering incorporating hormone therapy. Rather, they should do research and talk to others already offering such services in their practices.

CONCLUSION

As one transsexual woman explained, "It's not like my real body; it's like a mask I want to shed, and it's really hard because people just don't seem to understand." This sentiment is shared by many transpeople and demonstrates the need for an array of services to make them feel welcome; address their individual needs; and deliver the kind of comprehensive, culturally sensitive services the Ryan White HIV/AIDS Program was founded on.

Transmen and transwomen face significant health disparities and barriers in access, and Ryan White providers can ensure that patients receive the care and services they need. No one model of care delivery works for all transgender subpopulations, so doing research, enlisting the assistance of local trans-friendly agencies, and talking to members of this population will go far in helping craft an approach that best serves the needs—and wants—of a provider's transgender community.

Forthcoming changes to the CDC's HIV surveillance methodology are expected to include using the two-step model to collect data on sex assigned at birth, as well as current gender identity. These changes should ensure that transpeople who identify as male or female but not transgender are classified as transgender.[38,40] In addition, Section 4302 of the Patient Protection and Affordable Care Act (Pub. L. 111–148) seeks to create specificity, uniformity, and increased quality in data collection. These improvements, together with the U.S. Department of Health and Human Services national data progression plan (in development), will create a more comprehensive picture of trans health care needs and inform our health efforts in years to come.

FIGURE 1. BODILY CHANGES WITH HORMONE THERAPY

FOR MALE-TO-FEMALES	FOR FEMALE-TO-MALES
Increase in: breast size and body fat (which is redistributed, particularly to the hips) *Also, softening of skin*	*Increase in:* clitoris size, facial and body hair, sexual arousal, and upper body strength *Also, deepening of voice*
Decrease in: upper body strength, body hair, fertility, testicle size, and sexual arousal	*Decrease in:* hip fat, breast size, scalp hair (potential pattern baldness)
Risks: blood clotting, infertility, liver disease, hypertension, gallstone formation, diabetes mellitus, increased blood pressure, shift in lipid profiles, potential vitamin deficiency (including vitamin D and calcium), and potential to develop benign and malignant liver tumors and hepatic dysfunction.	*Risks:* ovarian cancer, infertility, and cardiac risk.

Risk of hormonal therapy not under a doctor's care include bacterial and viral infections from non-sterile injections; liver damage; blood clotting problems; deep vein thrombosis; and potential drug interactions.

Sources: Harry Benjamin International Gender Dysphoria Association. Standards of care for gender identity disorder (6th ed.). February 2001. Available at: www.wpath.org/Documents2/socv6.pdf. Accessed April 29, 2011. Transgender HIV/AIDS Health Services. Best practices guidelines. 2006. Available at: www.sfhivcare.com/PDFs/best_practices_guidelines_for_transgender_hiv_services.pdf. Accessed July 18, 2011. Makadon HJ, Mayer KH, Potter J, et al. *American Guide of Physicians. Fenway guide to lesbian, gay, bisexual and transgender health.* Vera Press, 2008.

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TRANSGENDER HEALTH ONLINE RESOURCES

American Medical Student Association Transgender Health Resources: www.amsa.org/AMSA/Homepage/About/Committees/GenderandSexuality/TransgenderHealthCare.aspx

Clinical Transgender Risk Assessment: www.pamaaetc.org/downloads/TRiskPocketGuide.pdf

Endocrine Treatment of Transsexual Persons: An Endocrine Society Clinical Practice Guideline: www.endo-society.org/guidelines/final/upload/Endocrine-Treatment-of-Transsexual-Persons.pdf

Fact sheets on prevention needs of male-to-female and female-to-male transgender persons: www.caps.ucsf.edu

World Association for Transgender Health (previously called the Harry Benjamin International Gender Dysphoria Association Standards of Care): www.wpath.org/Documents2/socv6.pdf

Institute of Medicine's *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding* report: www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx

Primary Care Protocol for Transgender Patient Care: http://transhealth.ucsf.edu/trans?page=protocol-00-00

Tom Waddell Health Center Protocols for Hormonal Reassignment of Gender: www.sfdph.org/dph/comupg/oservices/medSvs/hlthCtrs/TransGendprotocols122006.pdf

Transgender care: www.transgendercare.com

Transgender HIV/AIDS Health Services Best Practices Guidelines: www.sfhivcare.com/PDFs/best_practices_guidelines_for_transgender_hiv_services.pdf

Transgender Law 101: www.yescenter.org/TransgenderLaw.pdf

Center of Excellence for Transgender Health: www.transhealth.ucsf.edu/protocols

Vancouver Guidelines for Transgender Care: http://transhealth.vch.ca/resources/careguidelines.html

World Health Organization Transgender HIV Prevention Guidelines: www.who.int/hiv/pub/guidelines/msm_guidelines2011/en/

Yahoo Trans Medicine Group (for providers): http://groups.yahoo.com/group/transmedicine/

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